

**THE EXPERIENCE OF NEUROPSYCHOLOGICAL ASSESSMENT, VIEWS OF  
CLIENTS WITH NEURODEGENERATIVE CONDITIONS**

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## ABSTRACT

**Background:** It is estimated there are currently 2.6 million people living with a progressive neurological condition in England (Neurological Alliance, 2014). Neuropsychological assessment to detect associated cognitive changes are a primary aspect of care, yet little is known about how neuropsychological assessment is experienced.

**Aims:** This study captures the experience of undergoing a neuropsychological assessment from the viewpoint of clients with neurodegenerative conditions.

**Methodology:** Semi-structured interviews were conducted with eight people with neurodegenerative conditions, who had recently undergone a neuropsychological assessment. The transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

**Results:** Four interrelated superordinate themes emerged from analysis: expectations of assessment, relationship with clinician, experience during testing and outcome of assessment. Overall, the experience of neuropsychological assessment was characterised as emotional and intense experience, yet most talked about the process as a positive experience. Participants hoped the assessment would objectively measure suspected or 'hidden' cognitive deficits, to increase understanding and help them cope with potential impairments. Participants reported the relationship with the assessing clinician was vital in determining their experience and helping them to withstand the emotional stresses of testing. Participants described diverse experiences during testing, from enjoying a sense of retained ability, to feelings of frustration, stress and disappointment at perceived 'failure'. Various coping strategies were utilised to cope with the evoked emotions. The assessment environment was highlighted as important, with distractors felt to negatively impact performance. There was a sense the assessment provided objective 'proof' of the presence or absence of cognitive deficits, with accessible and prompt written feedback empowering participants to cope, adjust to difficulties and increasing relative's awareness. Participants described mixed responses to feedback, from a therapeutic sense of

relief, to feeling forced to confront the objective description of the impact of their condition. Despite participants reporting some negative aspects to testing, most emerged with a sense of having benefited from the experience.

**Implications and Conclusions:** The findings of the study are considered in light of existing research, with consideration given to future research opportunities. The implications for clinical practice and training are discussed, including recommendations of pre-assessment meetings to prepare clients for the process (including the emotional aspects), and testing to be conducted by a familiar clinician, with whom the client has built rapport, and who can provide reassurance to offset the inherent uncertainty over performance. Providing an optimal environment, and ensuring feedback is timely, comprehensible and meaningful were also found to be of importance.

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## **LIST OF ABBREVIATIONS**

Below is a list of the most commonly used abbreviations in the current study.

CNS = Central Nervous System

HD = Huntingdon's Disease

IPA = Interpretative Phenomenological Analysis

MND = Motor Neurone Disease

MS = Multiple Sclerosis

MSA = Multiple Systems Atrophy

NHS = National Health Service

PD = Parkinson's Disease

RCT = Randomised Controlled Trial

TBI = Traumatic Brain Injury

UEL = University of East London

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## **1. INTRODUCTION**

### **1.1. Overview**

This chapter will provide context, by firstly examining neurodegenerative conditions, including their classification, incidence, prevalence, aetiology, prognosis and impact. Following this, I will describe the process of neuropsychological assessment, before considering its application to clients with neurodegenerative conditions. The existing literature on the experience of neuropsychological assessment will be evaluated, focussing on the few existing studies including people with neurodegenerative conditions. I will consider the inclusion of people with neurodegenerative conditions in research, providing a rationale for the study's overall aims.

In keeping with the epistemological position, I will write in first person where required, to aid transparency and reflexivity as a qualitative researcher (Webb, 1992). The term participant, patient and client will be used interchangeably throughout. In addition, the terms 'neuropsychological', 'cognitive' and 'psychometric' assessment are often confused in both theory and practice, with psychometrics relating to the psychological measurement of various traits, and cognitive assessments used as a broad term for testing performed by various professions, particularly in educational settings (Boake & Block, 2015). For clarity's sake, I will use the term neuropsychological assessment to refer to the comprehensive standardised testing performed by clinical psychologists.

### **1.2. Neurodegenerative Conditions**

Broadly speaking, 'neurodegenerative conditions' is an umbrella term for diseases characterised by progressive and irreversible degeneration and/or death of neurones in the central nervous system (CNS; comprising of the brain and spinal cord), resulting in incurable and debilitating conditions. There is estimated to be several hundred different neurodegenerative conditions, yet attention has focused on the most common or publicised, classically Alzheimer's

disease, Parkinson's disease (PD), multiple sclerosis (MS), Huntingdon's disease (HD), motor neurone disease (MND) and multiple system atrophy (MSA) (Joint Programme Neurodegenerative Disease Research, 2017; Przedborski, Vila & Jackson-Lewis, 2003). Neuroanatomically, neurodegenerative conditions include the dementias, however in practice, a distinction is made between the dementias, which typically affect older adults versus neurodegenerative conditions that typically affect younger people and involve a significant sensory-motor component. Throughout this study, I will use the term neurodegenerative conditions to refer to the latter. The justification being that neuropsychological assessment plays a significant role in the diagnosis of dementia (and with considerable associated stigma), the experience of people with possible dementia, may be very different to that of people with other neurodegenerative conditions.

#### 1.2.1. Classification

The prominent types of neurodegenerative condition are outlined below, and are typically categorised using a combination of a clinicopathological approach (i.e. based directly on observable symptoms), and a topographical approach (i.e. based on the distribution of lesions). Unfortunately this can prove challenging, as the underlying pathological markers of disease, do not always correspond to observed symptoms. For instance, the brain of individuals diagnosed with one neurodegenerative condition, could also exhibit pathological characteristics for another (Greater Boston Physicians for Social Responsibility [GBPSR] & Science and Environmental Health Network [SEHN], 2008). Hence, the clinical and pathological characteristics exhibited often overlap, not discretely matching one condition, and the same neurodegenerative process can affect different brain regions, or several simultaneously, giving rise to varying symptoms, resulting in dramatically different clinical pictures (Przedborski et al., 2003). Therefore, although pathological analysis may be regarded as the gold standard in many diseases, it cannot meaningfully be applied to neurodegenerative conditions (Gómez-Rio, Caballero, Górriz Sáez & Mínguez-Castellanos, 2016), meaning diagnosis often relies on subjective clinical judgement.

Whilst it is appealing to believe that each neurodegenerative condition has distinct causes, characteristics and pathological features, the assumption of “one disease, one pathology” (GBPSR & SEHN, 2008, p.60) has been largely disregarded. Nevertheless, it continues to underpin the current diagnostic standards, resulting in a system that is inadequate in the vast majority of cases, and making differential diagnosis challenging, especially in early phases or atypical variants (Gómez-Rio et al., 2016). Further difficulties are encountered as symptoms are often mild and nonspecific initially, before growing progressively worse, hence there is uncertainty as to when symptoms warrant a disease label (GBPSR & SEHN, 2008).

Moreover, there is a lack of clarity around distinguishing neurodegenerative processes from ‘normal’ aging. For instance, amyloid plaques have been found to be the single greatest predictor of cognitive impairment, however plaques are also commonly found in seemingly healthy people (GBPSR & SEHN, 2008). It is possible these plaques do not occur ‘normally’, but represent a pre-symptomatic stage of disease which would’ve developed had the person lived long enough (Przedborski et al., 2003). Przedborski et al., (2003) concluded that although mild cognitive changes are common in elderly individuals, this does not make them ‘normal’, with studies showing very few plaques in individuals with no cognitive decline (Morrison & Hof, 1997), suggesting aging and neurodegeneration represent distinct entities.

Reliance on the current classification system has hampered early detection and hindered progress in identifying the causes and mechanisms underlying conditions. This is crucial for discovering and monitoring the efficacy of new treatments, when conditions may be most amenable to treatment (Noble & Burns, 2010). Furthermore, it has contributed to misdiagnosis, with up to 20% of patients diagnosed with PD found to have a different disorder at autopsy (Stacy & Jankovic, 1992). Without undermining the usefulness of the current classification system in providing a shared clinical language and peer support to those diagnosed, the poor correlation between pathological markers and clinical symptoms has prompted exploration of alternatives. A recent report suggested that rather than viewing neurodegenerative conditions as distinct entities, they

could be more meaningfully viewed on a continuum of age-associated cognitive impairment (GBPSR & SEHN, 2008). Alternatively, Przedborski et al. (2003) suggested a classification system based on molecular characteristics (e.g. disease of cerebral cortex, basal ganglia or cerebellum etc.), which can be further classified based on clinical features (e.g. dementing versus non-dementing), which they hoped would identify common mechanisms underlying the disease and open new treatment avenues.

*1.2.1.1. Parkinson's disease:* With the highest prevalence rate of any neurodegenerative condition, PD is the most common cause of a set of motor symptoms known as Parkinsonisms, which include tremor (usually beginning in the hands), bradykinesia (slowness of movement) and muscle rigidity (stiffness) (DeMaagd & Philip, 2015; NHS Choices, 2016b), as well as numerous non-motor symptoms suggested to occur during a preclinical phase (Schrag, Horsfall, Walters, Noyce & Petersen, 2015). Onset is typically between 50-60 years (although it can occur in young adults), with men at 1.5 times greater risk (Wooten, Currie, Bovbjerg, Lee & Patrie, 2004). PD predominantly affects dopamine-producing neurones in a brain area called the substantia nigra, resulting in reduced dopamine levels. As dopamine acts as a messenger to help control and co-ordinate movement, motor symptoms result, appearing after 80% of nerve cells have been lost (NHS Choices, 2016b).

*1.2.1.2. Multiple sclerosis:* MS is an autoimmune condition, in which the body's immune system mistakenly launches an attack directed against the myelin sheaths insulating nerves in the CNS (NHS Choices, 2016a). The resulting inflammation and damage disrupts and distorts nerve impulses traveling to the rest of the body, leaving behind scarring (sclerosis). Women are three times more likely to be diagnosed, typically in their 20s and 30s (NHS Choices, 2016a). With lesions disseminated in time and space, the course is highly variable and unpredictable; for some, symptoms develop and steadily worsen, whilst others experience periods of relapse and remission (Cosh & Carslaw, 2014; Goldenberg 2012).

*1.2.1.3. Huntingdon's disease:* HD is caused by a dominantly inherited faulty gene which results in damage to neurones. The offspring of carriers of the faulty gene have a 50% chance of inheriting the disease (Myers, 2004). The onset of symptoms is typically between 30-50 years and is usually fatal 15-20 years after symptoms start (NHS Choices, 2018).

*1.2.1.4. Motor neurone disease:* MND, as the name suggests, affects motor neurones, resulting in progressive weakness of limbs, bulbar and respiratory muscles, ultimately proving fatal, usually within three to five years (Shaw & Wood-Allum, 2010). There are four main types, with amyotrophic lateral sclerosis the most common (MNDA, 2017).

*1.2.1.5. Multiple systems atrophy:* MSA is caused by degeneration of nerve cells in several areas of the brain over time and is a fatal and rapidly progressing disease. Recent studies confirmed a key role of alpha-synuclein aggregation in the disease's development, which is thought to be responsible for the progressive and widespread cell loss (Wenning, Stefanova, Jellinger, Poewe & Schlossmacher, 2008).

## 1.2.2. Incidences and Prevalence

The Neurological Alliance (2014) estimated there are 2.6 million people living with a progressive neurological condition in England, of which 106,680 people are suffering from PD, 84,000 from MS, 6,580 from HD, 3,750 from MND and 2,520 from MSA. The most consistent risk factor for developing a neurodegenerative condition is increasing age (Tanner, 1992), although they vary significantly with each condition. It is difficult to assess incidence of neurodegenerative conditions, as many are not accurately diagnosed until the disease process reaches advanced stages. Even symptom onset, does not equate with onset of disease, which could have been occurring for several years before "residual neurones... fall below the number required to maintain normal functioning" (Przedborski et al., 2003, p.6-7). Unfortunately, lack of pre-symptomatic markers restricts the ability to determine 'true' onset, resulting in a prevalence diagnosis gap, hence actual numbers are almost certainly higher (McGovern Institute for Brain Research at Massachusetts Institute of Technology, 2014; Przedborski et al., 2003).

Furthermore, as neurodegenerative conditions primarily strike in mid to late life, and with continued population growth and an aging population, their prevalence is expected to soar (Bokde et al., 2011). For instance, the prevalence of PD is estimated to double by 2065 (Parkinson's UK, 2018). With the predicted rise in prevalence, the number of people living with long term disability will increase, resulting in substantial societal cost in the form of healthcare, lost productivity and carer burden (Findley, 2007). In the UK, the annual economic burden is estimated to be between £449 million to £3.3 billion for PD (Findley, 2007) and £3.3 to £4.2 billion for MS (MS Society, n.d.).

### 1.2.3. Aetiology

With few exceptions, the causes and mechanisms underlying the chronic progression of neurodegenerative conditions remains unknown (Gao & Hong, 2008). Even in cases where aetiology has been identified (such as the faulty gene responsible for HD), the mechanisms which provoke the disease onset are speculative, at best (Przedborski et al., 2003). Within the field, there is debate regarding the relative contributions of genetic versus environmental factors in the initiation of disease. Some conditions have an unmistakably familial occurrence, suggesting a dominant inherited (e.g. HD), recessive inherited or sex-linked disorder. Even some conditions which are essentially sporadic, show a small genetic element (e.g. PD or MND where 10% are familial) (Przedborski et al., 2003). For cases that are truly sporadic, many occur within geographic or temporal clusters, supporting the suggestion that toxic environmental factors are the likely cause. For instance, lack of sunlight/vitamin D and viral infections have been implicated in the occurrence of MS (NHS Choices, 2016a), and various toxic compounds and pesticides have been suggested to produce parkinsonian syndrome or elevate risk of PD, respectively (Brouwer et al., 2017; Kurtland, 1988; Przedborski & Vila, 2001). Yet, evidence linking environmental factors to PD remains inconclusive, with studies failing to show a definitive association (Tanner, 1989). Collectively, the findings suggest sporadic cases probably result from a combination of genetic and environmental factors, with environmental factors potentially influencing gene expression (Przedborski et al., 2003).



#### 1.2.4. Impact

The consequences of neurodegenerative conditions vary significantly between individuals, depending on the type, severity and region of CNS affected. However, they are commonly associated with deterioration across several domains, including physical (motor symptoms), cognitive (memory loss), emotional (apathy, depression and anxiety) and behavioural (disinhibition) symptoms (Levenson, Sturm & Haase, 2014). Physical impairments typically include movement, balance and coordination problems, fatigue, weakness, sensory loss, difficulties with swallowing, speech and vision, sexual problems and problems with functions controlled by the autonomic nervous system (e.g. breathing, blood pressure or bladder and bowel control) (Batista & Pereira, 2016). Cognitive impairments include difficulties with executive function (planning, organising and problem solving), learning and memory, language, visuospatial function, attention, concentration and information processing speed. Cognitive deficits occur in approximately 30-50% of patients (Broeders, Velseboer, De Bie & Speelman, 2016; Brown et al., 2010; Duff et al., 2010; Medical Advisory Board of the National Multiple Sclerosis Society, USA, 2008; Motor Neurone Disease Association [MNDA], 2018), with 10-15% developing an impairment severe enough to be considered early-onset dementia (Longley, 2007; MNDA, 2018). It has been suggested cognitive and behavioural changes are the most debilitating aspect, both for family's adjustment and the person's long-term functional outcome (Longley, Tate & Brown, 2012; Paulsen, 2011).

Whilst important to capture cognitive deficits, this does not capture the dramatic emotional and social impact, which extends far beyond obvious disease symptoms (Levenson et al., 2014; Welsh, 2001). The domains affected range from sleep (Schrempf, Brandt, Storch & Reichmann, 2014), mood (Baquero & Martin, 2015), personal self-care (Rao et al., 1991), social and leisure activities (Rao et al., 1991), interpersonal relationships and marital satisfaction (Chipchase & Lincoln, 2001; Schrag, Hovris, Morley, Quinn & Jahanshahi, 2003), employment (Rao et al., 1991) and driving (Schultheis, Garay, Millis & DeLuca, 2002) and can significantly impact on quality of life (Batista & Pereira, 2016). The wide-reaching affects, often impair people's ability to maintain essential life roles, giving rise to negative self-perceptions, lower emotional wellbeing and social

stigma which impacts not only individuals, but also families and societies (Batista & Pereira, 2016).

#### 1.2.5. Prognosis and Treatment

Most neurodegenerative conditions progress slowly over the course of several years, ultimately limiting life expectancy and affecting a person's ability to function to the extent that they may become dependent on care. It is likely the rate of neuronal death remains relatively stable throughout the course of the disease, with sudden symptomatic deteriorations explained when neuronal levels drop below a functional threshold (Przedborski et al., 2003). In some instances, death can result directly from the neurodegenerative condition impairing the ability of vital respiratory or cardiac functions, such as in MND. However, for a large majority, death is not attributed directly to the disease, but due to occurrence of secondary health conditions that result from motor and cognitive impairments, including fatal accidents and falling. There is no evidence neurodegenerative conditions increase the risk of developing common comorbidities, such as stroke, cancer or cardiovascular disease, which are the leading causes of death in developed countries (Przedborski et al., 2003).

Although the past few decades have seen considerable advances in understanding neurodegenerative conditions, significant challenges remain in their classification and treatment (Noble & Burns, 2010; Young, 2009). There are currently no cures for neurodegenerative conditions, but there are numerous disease modifying or symptomatic treatments, attempting to maintain quality of life. Unfortunately, prolonged use of recommended medications can cause debilitating side effects, and lack of knowledge regarding the causes of disease has hampered attempts at preventative approaches (Przedborski et al., 2003). Yet, the search for effective treatment continues with increasing urgency, and hope remains of a cure, amongst discoveries of innovative drug treatments and gene therapy trials.

### **1.3. Neuropsychological Assessment**

Neuropsychological assessment is the “normatively informed application of performance-based assessments of various cognitive skills” (Harvey, 2012, p.91). Typically, tests are administered in a battery approach, taking two to six hours, to assess a range of cognitive domains such as attention, processing speed, memory and learning, problem solving, visuo-spatial, language and executive functions. Neuropsychological assessments are commonly used to detect, assess and diagnose cognitive impairments resulting from neurological illness or injury, to help formulate treatment plans, aid clinical decision-making and monitor change (Lezak, Howieson, Bigler & Tranel, 2012). The specific tests selected generally depend on the referrer’s request, clinician’s preference and the issue pertinent to the client, with the underlying aim being to understand what brain regions and networks are involved in specific behaviours. Neuropsychological testing makes up a core component of clinical neuropsychologists’ work, and they are usually administered alongside observations of behaviour, self-report questionnaires and detailed clinical interviews to review pre-morbid functioning, medical background, and behavioural and emotional functioning.

The British Psychological Society’s (BPS; 2003) professional guidelines make numerous recommendations aimed at enhancing professional standards adopted by neuropsychologists. The guidelines cover the use of neuropsychological tests in clinical practice, medico-legal practice and research, and state only those with appropriate training and experience, familiar with associated literature and relevant manuals, should administer, score and interpret the tests. Additionally, all clinical neuropsychologists should take care to gain consent of the client prior to any discussion with family, carers and other agencies, and should take into consideration the client’s context, including age, diagnosis, ethnicity and social and cultural variables. As Lezak et al. (2012) notes, clinicians inevitably bring their own assumptions and biases to the process, hence they have an ethical responsibility to continually update their knowledge.

The process of neuropsychological assessment usually begins with the client being given verbal or written preparatory information, either in a separate session

or immediately beforehand (Schoenberg & Scott, 2011). Lezak et al. (2012) recommends this include straightforward and understandable explanations regarding the purpose and nature of the testing, the possible outcomes, confidentiality and a chance to explore the client's engagement with testing. Inadequate preparation may lead clients to misinterpret standardised assessment procedure, for instance clients may believe they are not being permitted access to necessary information for successful testing (Foran, Millar & Dorstyn, 2016). Clients will often bring a person of their choice during the clinical interview and feedback session, but best practice is for them to complete the testing session alone.

To support clients to perform their best, neuropsychological testing should be undertaken in optimal conditions: in a quiet, well-lit and ventilated room at a comfortable temperature. Unlike other medical assessments (e.g. a MRI scan), neuropsychological assessments have a uniquely relational element, meaning a thoughtful examiner can improve the situation. A competent clinician, should be mindful of anxiety, and prepared to intervene, putting people at ease with continual encouragement or random praise, and perhaps asking a simple question to maintain therapeutic rapport (Lezak et al., 2012). By creating a comfortable, patient-focused environment, clients will be inclined to provide a deeper level of information and may be more receptive to explanations and recommendations, enabling mutual understanding. It follows that client's satisfaction with testing increases if they feel confidence and trust in clinicians, and if there is ongoing dialogue and exchange of information (Roberts, Stiller & Dichiera, 2012). As highlighted, it is vitally important to pay attention and value subjective experience if we are to improve practice, yet it requires the skill of clinicians to carefully balance obtaining a comfortable environment whilst maintaining standardisation procedures (Kaufman & Lichtenberger, 1999).

Most neuropsychological tests are norm-referenced, meaning an individual's performance can be compared to that of his or her peers of the same age or educational level. Therefore, it is of vital importance that neuropsychological tests are administered in a standardised way to ensure reliability and validity of measures, and precision of subsequent interpretations. It is for this reason, the

dialogue between clinician and patient is highly structured, with clinicians encouraged to adhere to prescribed administration instructions used during test standardisation. This often includes specific instructions on wording, detailed directions regarding the presentation of test material and being strongly discouraged from revealing any feedback during the testing session.

Whilst this enables clinicians to discover the individual characteristics of each person's response, it might create a 'coldness' and affords little flexibility in offering emotional support to the client (Lezak et al., 2012). This can be anxiety provoking for the client, as given limited feedback, they may assume they are failing or displeasing the examiner, increasing anxiety and potentially compromising test performance (Bennett-Levy et al., 1994). In addition to anxiety, several other factors can affect test performance, including fatigue, distractions, awareness of poor performance and motivational variations. For instance, as the process is demanding and time consuming, those who fatigue easily may notice concentration diminishes and performance deteriorates (Paterson & Scott-Findlay, 2002). Awareness of these increased 'failures' can affect mood, not only interfering with performance, but potentially contributing to longer-term emotional consequences, with the stigma of cognitive impairment threatening self-esteem and leading to negative self-identity (Krohne et al., 2011).

It is also necessary to consider the limitations of neuropsychological tests. With the majority developed and norm-referenced in Western, English speaking cultures, the construct validity (the degree to which a test measures what it claims) is likely to vary according to ethnic group (Brickman, Cabo & Manly, 2006). Moreover, neuropsychological assessment may have a reduced value where physical disability is present, including difficulties with vision, hearing, speech and writing, which require a bespoke approach (Bokde et al., 2011). In addition, although tests attempt to use large samples for standardisation, the reality of normative data means scores falling in the extreme ranges (i.e. superior or impaired ranges) are compared to relatively little data, sometimes based on only a handful of individuals. Ceiling and floor effects can result in deceptive scores, especially for individuals with high or low pre-morbid functioning, where

scores may lack sensitivity or falsely exaggerate impairments, respectively (Bokde et al., 2011).

Whilst neuropsychological assessment may attempt to measure the underlying constructs of cognitive domains, there has been a shift towards focussing on what extent performance on tests correspond with real-life everyday cognitive function (ecological validity), rather than diagnosis. Unfortunately, the tests themselves have not been updated to reflect this, hence achieve only moderate levels of ecological validity (Chaytor & Schmitter-Edgecombe, 2003), not capturing the cognitive complexity required for many routine activities (Lezak, 1987). Furthermore, a purely test-centred approach, perhaps fuelled by a sense of professional 'ownership' of testing, risks overlooking social context, for instance the client's living environment, meaning any recommendations based solely on testing should remain tentative (Gass & Brown, 1992). With neuropsychological assessment typically presented as a benevolent process, often minimised as 'pen and paper puzzles' to relieve anxiety, it is important to advocate for a balanced description to ensure truly informed consent and relinquish some of the 'power' held by clinicians (Genevay, 1997).

The feedback session is a crucial part of the process, arguably forming an intervention in its own right. It is recommended that client-friendly feedback be provided in both verbal and written form (including a report to the client, GP and referrer), as well as providing space to discuss concerns and offering follow up support (Smith, Wiggins & Gorske, 2007; Westervelt, Brown, Tremont, Javorsky & Stern, 2007). Gass and Brown (1992) recommend six steps when providing feedback; reviewing the purpose, defining the tests, explaining test results, describing strength and weaknesses, addressing diagnostic and prognostic issues, and making recommendations. Unfortunately, numerous patients comment they never received feedback about their performance, with some receiving second-hand feedback from referrers, which can understandably increase patient's distress (Bennett-Levy, Klein-Boonschate, Batchelor, McCarter & Walton, 1994; Gass & Brown, 1992). There may be a reluctance to share feedback if it is ambiguous or undesirable (Krohne, Slettebø & Bergland, 2011; Smith et al., 2007), moreover it may prove difficult for patients who lack cognitive

capacity or educational background to process the feedback in a meaningful way (Henderson, Caplan & Daniel, 2004); yet one could argue it is unethical to withhold.

### 1.3.1. Neuropsychological Assessment in Neurodegenerative Conditions

Although physical impairments are the most obvious deficit, it is cognitive, behavioural and emotional deficits, with their high prevalence and persistence, which have a significant impact on functioning and predict long-term outcome (Paulsen, 2011). With neuropsychological assessment evaluating cognitive function and considering behavioural and emotional difficulties, it is valuable for people with neurodegenerative conditions and their families in several ways. Firstly, as neurodegenerative diseases have specific and sometimes distinct profiles of cognitive change depending on the pattern of cerebral deterioration, assessment can be of value in diagnosing the type of disease, differentiating it from other organic (i.e. dementia) or nonorganic causes (i.e. affective disorders) (Bokde et al., 2011). Secondly, repeated testing can detect subtle cognitive deficits (American Academy of Neurology, 1996), and assess rate of change overtime, with deterioration over that expected from aging suggestive of a degenerative process (Bokde et al., 2011). Thirdly, assessment can provide information on the daily functional consequences of the disease, provide targets for support, hence informing treatment. Finally, it can assist in making practical decisions regarding a person's ability to function independently and guide recommendations on capacity issues (Bokde et al., 2011).

Whilst test administration is highly standardised, the specific referral pathways, timings of assessments and process protocols vary case by case depending on clinical need and service context. For instance, the timing of administration of an assessment is likely to reflect its varied functions throughout the disease course, with early testing assisting in diagnosis or aiming to achieve a baseline against which future assessments can be compared. The inconsistencies in referral pathways are important to consider, as the way in which a client learns about their referral (and whether they agree it may be beneficial) can evoke diverse responses in cooperation, anxiety and trust, affecting test performance (Hartfield, Cason & Cason, 1982).

Despite recent calls for a more harmonious approach (Costa et al., 2017), debate continues over how neuropsychological assessment is best utilised with neurodegenerative conditions. Many clinicians favour a flexible battery, arguing it appropriate (and economically beneficial) to solely administer tests that relate to the patient's specific complaints, yet others argue this simply confirms the existence of readily observed symptoms (Reitan & Wolfson, 2001). Reitan and Boll (1971) recommend every patient should benefit from a comprehensive battery, utilising both specific and general tests, covering a full range of neuropsychological functions, to gain a holistic understanding of intra-individual differences in performance. With motor symptoms alleviated relatively simply in PD, it is critical to ensure cognitive deficits do not lag behind, creating a 'weak link', preventing functional impairment (Reitan & Wolfson, 2001). Similarly, with studies in MS demonstrating many cognitive deficits are unsuspected or unconfirmed (Longley, Tate & Brown, 2012; Peyser, Edwards, Poser & Filskov, 1980), comprehensive neuropsychological assessment can be crucial to detect, objectively confirm and monitor cognitive deficits.

Certainly, clinicians have ethical responsibilities, including to avoid harm to patients, to be competent in test selection, administration and interpretation, to ensure appropriate documentation of results and to avoid release of raw data (Binder & Thompson, 1995). More specifically, where neurodegenerative conditions are concerned, the number of controversies regarding classification, aetiology and assessment can result in inconsistencies and variation across clinicians, which could also be considered an ethical issue (Wong, 2006). For instance, ethical debates continue regarding appropriate test selection, including whether to offer a flexible or comprehensive battery, whether assessment should be functionally or diagnostically driven, at what stage of disease and how often assessment should be offered, and whether it is ever appropriate not to offer (especially if there is reason to believe the outcome would be unhelpful). With such variations certain to impact patient's experience, the American Psychological Association's (2002) ethical standards encourage clinicians to undertake necessary preparation when working with a new client group, by



becoming familiar with and carefully considering the entire spectrum of existing literature, empirical findings and associated controversies.

#### **1.4. Literature Search**

I conducted a literature search using psychological and medical databases; PsychINFO, Academic Search Complete, CINAHL Plus via EBSCO and ScienceDirect, Cochrane Library, Scopus, and MEDLINE. The following search terms were used in various combinations, using the Boolean operators 'AND' and 'OR';

- Neuropsychological assessment
- Cognitive assessment
- Client satisfaction
- Satisfaction
- Experience
- Neurodegenerative diseases

The search strategy also included reviewing reference lists and citations of relevant articles and searching widely using internet browsers (Google Scholar) and open source repositories (Research Gate, EThOS) to find additional relevant articles, conference papers and unpublished work. Results were limited to articles in English, with participants aged 18+. The results were not limited to peer-reviewed articles so as not to exclude doctoral theses which have made an important contribution to this area of research. However all studies were thoroughly scrutinised to ensure research quality.

A total of 181 articles were identified via EBSCO, and 208 using ScienceDirect, Cochrane Library, Scopus and MEDLINE. All titles and abstracts were examined for relevance and articles were included if clients were asked about some aspect of their experience of the neuropsychological assessment process. As the literature is limited, both qualitative and quantitative research articles were included. Articles that referred solely to experiences of diagnosis and post-diagnosis adjustment or to experiences of people without neurodegenerative conditions or dementia were excluded.

### **1.5. Existing Research on the Experience of Neuropsychological Assessment**

The earliest known studies to consider the experience of neuropsychological assessment were conducted by Bennett-Levy et al., (1994) and Donofrio, Piatt, Whelihan and DiCarlo (1999). For both studies, it has not been possible to establish if the sample included participants with neurodegenerative conditions, hence their exclusion from the subsequent literature review, however they have been summarised below to provide historical context.

Bennett-Levy et al. (1994) involved 129 outpatients, with various diagnoses (including stroke and head injury) from five centres across Australia. Participants who had undergone neuropsychological assessment 0-6 months previously, completed a Neuropsychological Assessment Questionnaire developed by the authors, mainly comprising of yes/no questions with the option to provide additional comments. Overall 56% described their experience as positive, with 91% describing it as positive or neutral. Between 39%-60% of respondents felt adequately prepared for the length and purpose of the assessment respectively, yet a worrying 60% reported they were not told what to expect. Most participants found it relevant (70%) and interesting (72%), with half reporting it was tiring (52%) and frustrating (47%). A large proportion of participants (75%) reported little or no anxiety about the assessment. In terms of feedback, 68% reported receiving feedback, yet only 26% received this in writing with most indicating they would have liked to.

Bennett-Levy et al. (1994) concluded that a positive experience was dependent on the degree of reported preparation and perceived *usefulness* of feedback. Several recommendations were made, including that clients are adequately prepared, given an adequate rationale and provided with written, understandable feedback. The authors acknowledged the lack of data regarding reliability and validity of the questionnaire, the overreliance on closed questions and omission of potentially important parts of the assessment process (e.g. qualities of the examiner), which may have impacted on the experience reported.

Donofrio et al. (1999) investigated client's perceptions of feedback following neuropsychological assessments. Sixty participants with 'brain dysfunction', referred to a neuropsychology clinic, were asked to complete a one-page questionnaire immediately following feedback. All participants reported finding the feedback session helpful or very helpful, with 95% finding the recommendations helpful, and 96.7% finding a written summary helpful. Feedback was unaffected by participants gender, diagnosis or the clinician's level of training. This study indicates overall satisfaction with feedback and highlights the importance of it being summarised in written form. Unfortunately, due to only a summary format being available, the quality of this study could not be appraised.

More recently, Mountjoy, Field, Stapleton and Kemp (2017) conducted a service evaluation of an outpatient clinical neuropsychology service, although again the study did not specify whether the sample included people with neurodegenerative conditions. Self-report questionnaires were developed and administered to 24 clients and 17 carers/family members immediately following feedback and again after three weeks. Of all responses, 81.5% and 90% were positive from clients and carers/family members respectively, with comments that the experience was 'very helpful' and 'interesting'. Overall findings highlighted neuropsychological assessment was experienced as clinically meaningful, with 88% of clients reporting their symptoms made more sense afterwards, although this understanding appeared to 'wear off', with only 72.7% of clients reporting the same after three weeks. Whilst this a likely consequence of legitimate memory problems and natural processes of forgetting, it was also mirrored in carers/family members reports, highlighting the importance of summarising findings for people to take away. In terms of the studies rigour, the developed questionnaire's psychometric properties remain unknown and a self-selecting bias may have been present.

Following early studies, the literature has diversified with studies examining the experience of neuropsychological assessment in various populations, including people with suspected dementia (Keady & Gilliard, 2002; Robinson, 2016),

people with traumatic brain injury (TBI; Owen, 2012), children (Conniff, 2008), people with learning disabilities (Davidson, Smith & Burns, 2014) adults with attention-deficit/hyperactivity disorders (ADHD) and autism spectrum disorders (Holst, Nyman & Larsson, 2009), culturally deaf people (Smith, 2010), older adults (Krohne et al., 2011) and people from different cultures (Dudley, Wilson & Barker-Collo, 2014; Shepherd & Leatham, 1999).

These studies used varying approaches, with some novel designs, for instance Conniff (2008) and Owen (2012) interviewed children and survivors of TBI respectively, and utilised interpretative phenomenological analysis (IPA) to explore experience of neuropsychological assessment. In Conniff's (2008) study, it emerged children experienced the reasons behind the process of testing as benign, although there was an overriding sense of uncertainty about what to expect and the implications of the testing. Children described positive experiences relating to qualities of the examiner and the test environment, and negative experiences relating to the length of testing. Overall children reported learning from the experience, although they found the varied difficulty of tests hard to manage, and described the experience as unusual and distinct from other testing experiences.

Owen's (2012) study highlighted the impact of the relationship with the examiner, with participants valuing a familiar examiner, who treated them as an equal, whilst an unfamiliar examiner caused uncertainty and anxiety. Participants approached the test with a need to try their best, and reported a range of feelings, from anxiety, confusion and frustration, to eagerness and relief. The tests were experienced as providing awareness regarding their injury, although participants spoke about factors that negatively affected the assessment, such as fatigue and a poor environment. Both studies recommended pre-assessment meetings (including written information) to prepare clients, build rapport and explore the person's feelings towards testing, as well as involving them directly in feedback sessions. A full exploration and critique of this literature is beyond the scope of this thesis, hence only literature specific to the experience of people with neurodegenerative conditions will be presented below.

#### 1.5.1. Existing Research on the Experience of Neuropsychological Assessment for People with Neurodegenerative Conditions

The above studies have provided valuable information about the experience of neuropsychological assessment, yet there is a paucity of literature into the experience of neuropsychological assessment, from the viewpoint of clients with neurodegenerative conditions. In fact, most research on neurodegenerative conditions focusses on the medical aspects, neglecting to consider the perspective of people with neurodegenerative conditions. The literature search identified five relevant pieces of literature that met search criteria (see Section 1.4), four studies explored experience of neuropsychological assessment via a survey or questionnaire (one in the context of a service evaluation and two in comparison to control groups) and one used IPA to analyse interviews.

Westervelt et al. (2007) examined perceptions of 129 clients and 80 significant others who had undergone a neuropsychological assessment at an urban neuropsychology centre in the United States of America. Participant's diagnoses included dementia, epilepsy, TBI, tumour and demyelinating disease. The surveys, designed by neuropsychology staff to assess patient satisfaction, were sent one month after the feedback session and comprised nine questions regarding scheduling of appointments, the assessor, the assessment environment, feedback session and recommendations. Participants were invited to write comments and rate each item on a four-point scale ranging from 'very much satisfied' to 'not at all satisfied'.

Overall, clients and significant others viewed the neuropsychological assessment positively, with 71% and 76% respectively, reporting they were very satisfied, irrespective of the assessor's experience. Clients commented on their appreciation of sufficient time being spent reviewing results, finding a detailed understanding of strengths and weaknesses confirmatory, although they were unsure whether it helped them understand or deal with their condition. Most reported they had followed, or planned to follow recommendations provided, although participants appeared more likely to follow recommendations that were simple, concrete and regarding patient safety, rather than pertaining to patient coping. Negative comments focused on the environment (e.g. room temperature)

and length of assessment. Unfortunately, with the studies inclusion of patients with a wide range of conditions, the views of people with neurodegenerative conditions makes up less than 5% of the sample and does not provide an account of their experiences specifically.

Foran et al. (2016) developed a patient satisfaction scale as part of a service evaluation and explored satisfaction of 66 out-patients following neuropsychological assessment, in a hospital-based neuropsychology service in Australia. Participants included in the postal survey, had mild to moderate cognitive impairments resulting from a variety of conditions, including dementia, TBI and MS. The scale, initially comprised of 24-items based on previously available patient satisfaction measures and theoretical literature, was reduce to 14-items following a focus group of 15 adult service users. Participants were asked to rate each item on a five-point scale (ranging from 'strongly agree' to 'strongly disagree'), were asked how they received feedback and were encouraged to provided further comments regarding their satisfaction via the use of two open-ended questions.

Overall satisfaction was high, although participants viewed the testing phase significantly more favourably over the pre-assessment and feedback phases. Female participants reported significantly lower satisfaction levels compared to males. With regards to feedback, 44% discussed the results with their neuropsychologist, 38% with a third party (e.g. GP, referrer or family) and 18% reported receiving no feedback or being unable to recall feedback. Thirty-two participants included additional remarks, with positive comments focusing on the clinician's interpersonal communication skills such as their professional manner, organisational skills and explanatory style. Dissatisfaction was reported with the service availability, physical environment and with feedback sessions being difficult to understand and emotionally draining. This study highlights the importance of pre-assessment preparation to provide personalised explanation regarding rationale and expectations, to reduce anxiety and potentially increase validity of the testing. Foran et al. (2016) recommend that whilst assessments are standardised, the way they are applied can be flexible and individualised, with oral and written feedback tailored to a person's strengths and weaknesses. Yet

again, the studies broad inclusion of various conditions results in a small representation of people with neurodegenerative conditions, namely MS.

The two survey-based studies cited above (Foran et al., 2016; Westervelt et al., 2007) present with several limitations. Due to low response rates, potential bias may exist in the sample, as responders may have been more likely to report positive experiences. Besides, a lack of anonymity may have resulted in participants being reluctant to express dissatisfaction, especially in the study by Foran et al. (2016) where the survey focused on positive aspects on the assessment process. As both studies were retrospective, they rely on participant's memory, which may affect reliability of the data, and as the surveys psychometric properties have not been examined, the content and construct validity remain unknown.

Rosado et al. (2017) examined perceptions of 218 clients on the day of their neuropsychological assessment at a neuropsychology clinic in Chicago. Participant's diagnoses included stroke, head injury, dementia, MS, depression and ADHD. A total of 84 participants (38.5%) repeated the questionnaires six weeks later, 49 of which had attended a subsequent feedback session and 35 had chosen not to. The self-report questionnaires asked participants regarding any changes in symptoms, functioning, ability to cope and satisfaction with services and recommendations. The findings showed participants who returned for feedback reported greater understanding of their condition, improved quality of life and ability to cope, compared to those who did not attend for feedback, highlighting that feedback should be considered an indispensable component that positively influences patient outcomes. As with the above studies, this study suffered high attrition and with participants not randomly allocated, selection bias may exist. Furthermore, contextual factors that may have prevented attendance at feedback sessions, such as access to transport, child-care issues, increased financial burden and work responsibilities were not assessed.

Longley, Tate and Brown (2012) developed a protocol for measuring psychological benefit of neuropsychological assessments in MS and subsequently presented results in a conference paper (Longley, Tate & Shaw,

2012). The prospective single-blind randomised controlled trial (RCT) explored responses to recommendations by randomly allocating participants to either a neuropsychological assessment with feedback or a 'sham wait-list' control. A total of 41 patients with MS and 35 caregivers were recruited from MS Australia. A variety of self-report questionnaires looking at the helpfulness and adherence of recommendations, demographics, MS status, psychological and cognitive variables, were administered via telephone, both prior to and after the neuropsychological assessment. Overall both patients and caregivers rated recommendations as moderately to very helpful, with 69% of patients and 64% of caregivers reporting adherence. There were indications that adherence may be predicted by caregivers' ratings of the patient's cognitive impairment and effort, although no findings were statistically significant. Whilst this single-blind RCT endeavoured to be methodologically sound, it did not allow for participants to provide rich accounts of their experience and participants that agreed to take part may have been generally more motivated to comply (and follow recommendations).

With the studies considered so far (Foran et al., 2016; Longley, Tate & Brown, 2012, Rosado et al., 2017; Westervelt et al., 2007) each is based in a single service, limiting generalisability of findings, and reliance on questionnaires means they mainly capture consumer satisfaction as a measure of quality assurance to evaluate service delivery. Whilst some studies invited qualitative comments, all utilised closed questions to some extent, imposing areas of perceived importance, preventing other more relevant areas being raised, and potentially limiting rich nuanced descriptions of experience.

Blake's (2004) doctoral thesis was amongst the first to utilise IPA to explore experience of neuropsychological assessment from the patient's perspective. Nine adults, with varying conditions including stroke, TBI and MS, were interviewed following neuropsychological assessment at an outpatient service in the UK. Findings indicated patients were poorly prepared for neuropsychological assessment, however patients approached it with positive expectations that it would provide information to help understand and cope with impairments. The relationship with the psychologists emerged as key in determining the quality of



their experience, and facilitated increased awareness of cognitive strengths and weaknesses. Blake (2004) recommended patients be sent preparatory information in advance and explore with patients what they hope to gain from testing. In line with IPA, this exploratory study recruited a small sample, hence it is not possible to make generalised claims about *all* patient's experiences of neuropsychological assessment. Furthermore, the homogeneity of the sample is questionable as several participants were awaiting feedback of results which arguably forms an important part of the process, and participants had varying conditions, hence may have experienced the process very differently.

## **1.6. Summary**

Examining the existing literature highlights that neuropsychological assessments are rarely experienced as a neutral event, with the process often experienced positively, and frequently described as 'helpful', 'interesting' and facilitating awareness of cognitive strengths and weaknesses (Bennett-Levy et al., 1994; Westervelt et al., 2007). Adequate preparation for the assessment and feedback of results, both verbal and written, emerged as important elements to reduce anxiety and improved outcomes for clients (Foran et al., 2016; Rosado et al., 2017). The assessment environment, service availability, length of assessment, fatigue, frustration and the clinician's interpersonal communication were reported as having a noticeable impact on the experience of testing (Bennett-Levy et al., 1994; Foran et al., 2016; Westervelt et al., 2007).

Whilst the growing body of literature is beginning to provide insights, it tantalisingly leaves us with many questions and gaps in our knowledge. For instance, several studies reported participants found the process helpful, yet did not specify what was learnt or in what ways it was meaningful in their everyday lives. Furthermore, most of the studies are quantitative, utilising surveys and questionnaires, and whilst a small number include a qualitative element, very few are formally qualitative. Hence, there is clearly scope for in-depth qualitative exploration of client's accounts, which may shed light on how neuropsychological assessment may contribute to improved quality of life, how it changes patient's views of themselves, or how qualities of the examiner may influence the process.

### **1.7. Rationale**

The literature review identified a paucity of research providing in-depth accounts of people's experience of neuropsychological assessment. Research has tended to recruit broad samples of participants with varying diagnoses from neuropsychology services, however as Bennett-Levy et al. (1994) points out, satisfaction will likely differ between client populations. Yet to my knowledge, there is no known study that has specifically explored how a person with a neurodegenerative condition experiences the assessment process, and this forms the basis of the rationale for this study.

Previous studies suggest the context of assessment may affect how it is experienced (Bennett-Levy et al., 1994), hence it is essential to consider the broader context of being assessed in relation to a neurodegenerative condition, a diagnosis which by its very nature is progressive. As assessments are conducted over the course of worsening disease, people may perform poorly, and the testing may vividly highlight and act as a painful reminder of lost ability and the potential of continued future loss. Furthermore, clients with neurodegenerative conditions may encounter specific disadvantageous features, for instance testing that requires fine motor skills in the face or motor symptoms. Therefore, the experience for people with neurodegenerative conditions, may be very different to other conditions, in which the trajectory is one of recovery or stability. Furthermore, due to the progressive nature of the disease, people with neurodegenerative conditions are likely to return for further episodes of care across their lifetime, hence the importance of understanding their experience specifically, as it is likely to be one that is repeated, having the potential to further consolidate negative experiences.

Furthermore, the current study considers specific methodological weaknesses of the previous research. For instance, quantitative approaches cannot encompass the study of human experience (Moustakas, 1994), and besides, the use of structured questionnaires are more likely to pose difficulties for participants with possible cognitive impairments (Paterson & Scott-Findlay, 2002), providing

unreliable or superficial results. Utilising qualitative interviews in the current study, provides participants a better opportunity to express the uniquely individual aspects of their experience, and gives voice to their unheard ideas, demonstrating their views are valued. This constitutes an important basis for future research (Nochi, 1998), promoting participant welfare, shifting the power dynamic, so participants become treated as active “partner[s]...rather than as subjects” or passive recipients (Keady & Gilliard, 2002, p.24).

Additionally, with the prevalence of neurodegenerative conditions set to increase rapidly (Bokde et al., 2011) and a trend towards increased provider accountability and emphasis on consumer satisfaction (Westervelt et al., 2007), it is crucial to consider how neuropsychological assessment can be most valuable. It is hoped this research can inform clinical practice, raising clinician’s awareness of the patient’s experience, thereby improving the quality of the service provided. For instance, if a clinician can be mindful of what a patient is experiencing, they can shape the assessment and delivery of results, to maintain patient involvement, enhance client’s understanding and maximise compliance with recommendations, ultimately benefitting the patient’s quality of life (Foran et al., 2016; Westervelt et al., 2007). Finally, in context of funding pressures facing the NHS following a decade of austerity, it makes good business sense to pay attention to patient’s experience to demonstrate the value of clinical neuropsychology (Prigatano, 2000; Westervelt et al., 2007).

## **1.8. Research Aims and Questions**

This study aims to;

- examine people with neurodegenerative condition’s accounts of the neuropsychological assessment and how they describe these experiences,
- explore their understanding, meaning and perceived usefulness of the assessment,
- address the gap in current research by contributing significantly to the evidence base through qualitative research.

The primary research question is;

- What do people with a neurodegenerative condition say about their experience of neuropsychological assessment?

The secondary research questions are;

- How do they describe this experience?
- How did the experience make them feel?
- What was their understanding of why they were assessed?
- What do they find helpful or unhelpful about the process?

## **2. METHOD**

### **2.1. Overview**

This methodological chapter will begin by outlining the epistemological framework adopted in this study and explore the rationale for selecting IPA as the qualitative tool of choice. I will then consider the research design and procedure before discussing ethical considerations. Lastly, I will describe data collection and analysis, including the reflexivity of the researcher.

### **2.2. Epistemological and Ontological Position**

Epistemology refers to “the way in which people gain knowledge about the world and come to regard some beliefs as true and others as false” (McLeod, 2005, p.28). Varying epistemological frameworks serve as lenses through which we view the world, each holding different assumptions that guide our thinking (Mertens, 2005). The following epistemological positions – positivist, post-positivist, critical realist and constructionist – can be viewed on a continuum between a scientifically objective versus a socially constructed world view. Positivism states there is an objective reality that exists independently of our representations and that phenomena can be predicted via valid ‘scientific’ inquiry. However, in its pursuit of objectivity, positivist researchers risk treating participants as objects, failing to acknowledge their own position in the research (Robson, 2011). Post-positivism accepts reality can only be measured imperfectly and will be influenced by the researcher’s beliefs and values, yet similarly to positivism, is a reductionist and deterministic philosophy. Critical realism takes the position that whilst there is a ‘reality’, it must be considered within broader historical, social, political and cultural contexts, hence it can explain how people may experience the same situation differently depending upon the meanings they attach to the situation (Willig, 2008). Finally, social constructionists assume there is no one truth, but multiple realities constructed socially, via language and within historical, cultural, political and gender norms.

In relation to the current study, the origins of qualitative approaches lie within the realm of post-positivist approaches, hence a critical realist epistemology was adopted. This will impact assumptions about what the data can tell us, shaping the research questions and ultimately influencing my 'gaze' as a researcher (Smith et al., 2009). The critical realist perspective accepts there is a stable, external world that exists independently of human conceptualisation (Danermark, Ekström, Jakobsen & Karlsson, 2002). For instance, this study does not deny the reality of neurodegenerative conditions, including the progressive and irreversible degeneration of neurones and the resulting symptomology, nor does it deny people's lived experience of neuropsychological assessment. At the same time, critical realism acknowledges the way reality is perceived, particularly in the social realm, is filtered through our own and other's life experiences, and hence depends on individual beliefs and expectations (Bunge, 1993). For instance, the study acknowledges that participants may attach different meanings to their experience, and that my interpretations as a researcher will be influenced by my own experience. Finally, a critical realist approach recognises that whilst constructs, such as the various neurodegenerative diagnoses and cognitive domains, hold some basis in reality, they are also heavily shaped by the broader social, cultural and political context.

### **2.3. Selecting a Methodology**

In keeping with the research aims and epistemological framework, this study will use qualitative analysis in the form of IPA, which is predominantly underpinned by a critical realist position (Shinebourne, 2011). There is a growing body of IPA research within clinical, counselling and health psychology demonstrating its value in psychological research, with detailed guidelines (Smith, Flowers & Larkin, 2009) facilitating its use with 'novice' researchers. It acknowledges an interactive element between the researcher and participants, and is well suited to capture in-depth accounts of individual's experience. Furthermore, I was drawn to IPA as it recognises data is generated as a product of a participant-researcher interaction, flattening power imbalances and acknowledging the researcher's explicit role in interpretative input which requires creativity and reflexive awareness (Larkin, Watts & Clifton, 2006).

### 2.3.1. Qualitative Analysis

Qualitative methodologies aim to understand and represent people's subjective experience, as close as possible to their perspective (Elliott, Fischer & Rennie, 1999) and lend themselves to exploratory research. This is particularly important in this study as people with neurodegenerative conditions experience of neuropsychological assessment has been a relatively neglected area of research, resulting in a deficiency of psychological knowledge (Smith, 1996). Qualitative research has the potential to give voice to previously unheard voices (Willig, 2008) and discover reasons for the outcome of interventions (Starks & Brown Trinidad, 2007).

### 2.3.2. Interpretative Phenomenological Analysis

Developed by Smith and Osborn (2003) and Smith et al. (2009), IPA seeks an 'insider perspective', examining human lived experience in detail (Pietkiewicz & Smith, 2012). It was considered a suitable methodology, as the aim of IPA is not to examine a predetermined hypothesis using a large sample, but to explore in-depth how a limited number of participants make sense of their world (Smith & Osborn, 2007). It views people as experts on their own experiences who can "offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words" (Reid, Flowers & Larkin, 2005, p.20). IPA lets people speak for themselves, whilst recognising it cannot do this directly or completely as the researchers own values, experiences and beliefs will influence interpretations and sense-making (Malterud, 2001; Smith, 1996).

IPA, with its theoretical roots in transcendental philosophy, is founded on three principles; phenomenology, hermeneutics and idiography (Smith, 2011).

Phenomenology is a philosophical approach to the study of experience and is concerned with what a human experience is *like*. Hermeneutics refers to the theory of interpretation which occurs at several stages throughout the research process, firstly by participants making sense of their worlds and subsequently by the researcher trying to make sense of the participant trying to make sense of their world (double hermeneutic process) (Smith & Osborn, 2007). Idiography is

concerned with the 'particular' ('particular' experiential phenomena, from the perspective of 'particular' people, in a 'particular' context, with a 'particular' sense of detail), as opposed to making claims at a group level (Smith et al., 2009). Hence IPA utilises small purposively-selected samples, focussing on distinctions or commonalities across individual's experience, before cautiously generalising without taking claims out of context, to help gradually build a picture for larger populations (Smith et al., 2009).

### 2.3.3. Limitations of IPA

Indeed, IPA has limitations in that it describes people's lived experience without attempting to explain it. However, it could be argued, to begin explaining an experience, you need to understand how individuals views their experience. In addition, IPA risks underplaying the role of language as constructing, not merely describing reality, and whilst it acknowledges the participants and researchers own values influence how an experience is described and interpreted, there is limited guidance about how to integrate this into the research process (Willig, 2008).

### 2.3.4. Why IPA Over Other Qualitative Approaches?

The phenomenological approach in IPA was deemed the most suitable approach to meet the research aims, over numerous qualitative alternatives, including Grounded Theory (GT), Thematic Analysis (TA), Discourse Analysis (DA) and Narrative Analysis (NA). GT originates from a sociological approach, rather than a psychological one and focuses on generating theoretical explanations that captures social processes, rather than understanding of individual experience (Starks & Brown Trinidad, 2007). It aims to achieve saturation, which would be logistically difficult and unnecessary to understanding people's lived experiences. TA focuses on identifying patterns of behaviour across larger samples and is mainly descriptive (Braun & Clarke, 2006), whereas IPA is better suited to a higher level interpretive complexity and its idiographic stance can capture richness of experience (Vaismoradi, Turunen & Bondas, 2013). DA attempts to understand the role of language in constructing reality and negotiating knowledge, meaning and identities, and similarly NA is used to understand how people use language or 'self-accounts' to construct and interpret the world



(Burck, 2005). Whilst IPA acknowledges the role of language, it is not concerned with every utterance, and allows greater flexibility to consider how language assists meaning making of experience (Smith et al., 2009).

## **2.4. Design**

The study utilised a cross-sectional qualitative design, utilising IPA to analyse data from semi-structured interviews with eight participants.

### **2.4.1. Service User Consultation**

During the study development, a service user consultation was arranged to obtain feedback regarding the research documents and interview schedule. The only suggested amendments, which were duly made, were to reduce repetition in the documentation and reduce the amount of time following the interview during which participants can withdraw their data.

## **2.5. Participants**

### **2.5.1. Recruitment**

Participants were recruited from a community neuropsychology service in central London that accepts referrals locally. Recruiting via a single service, and attending weekly multi-disciplinary team meetings during the recruitment phase, allowed for development of good working relationships with the team. This enabled clinicians to be reminded of the study (see Appendix A for staff information sheet), gain answers to questions and feel comfortable in suggesting potential participants. The clinical psychologists, who routinely completed neuropsychological assessments, approached potential participants that fulfilled inclusion criteria (see below) to discuss the study and, if they gave permission, provided their contact details to me. Potential participants who agreed to be contacted were subsequently sent a cover letter and participant information sheet (see Appendix B and C) and later contacted via email or telephone to arrange the interview if they wished to take part.

### 2.5.2. Sample

Qualitative interviews generally produce large volumes of data, requiring detailed and extensive analysis, hence it is appropriate to recruit a small number of participants to ensure voices are not lost (Larkin et al., 2006).

For IPA specifically, Smith et al. (2009) suggest conducting between 4-10 interviews for doctoral research, which allows for more detailed analysis of similarities and differences across cases. Based on this and peer review feedback, it was decided eight participants would be recruited for the study.

In line with recommendations for IPA (Smith et al., 2009), the aim was to recruit a reasonably homogenous sample, selected purposively due to the experience of a similar life event. This led to deliberations about the ways in which individuals differ from one another and how much variation can or needs to be contained to enable analysis of a phenomenon. As the population is likely to be small, this was largely dictated by a pragmatic need to balance homogeneity of the sample with the availability of potential participants, hence inclusion criteria were carefully selected to be inclusive. Nevertheless, reasonable homogeneity was achieved in that all participants were adults with a neurodegenerative condition for which they had undergone a neuropsychological assessment. Furthermore, the intention was not to achieve a representative sample, as IPA aims not for generalisability, but to “say something in detail about the perceptions and understanding of this ‘particular’ group rather than prematurely make more general claims” (Smith & Osborn, 2007, p.55).

### 2.5.3. Inclusion Criteria

- Adults (18+)<sup>1</sup> who have a neurodegenerative condition, and have undergone a neuropsychological assessment subsequent to their diagnosis (>1month, <2 years since assessment) which they can remember.

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<sup>1</sup> An upper age limit was not applied as it was felt a homogenous group could be achieved without an arbitrary limit which discriminates against older adults (McMurdo, 2012), and would exclude a large proportion of eligible participants.

- Participants should not have a pre-existing cognitive deficit that is unrelated to the potential deficit being assessed, or have exhibited possible confounding factors (e.g. suspected low effort).
- Participants should be able to verbally express themselves sufficiently to answer interview questions.
- Participants should be able to speak and understand English.<sup>2</sup>
- Participants should have capacity to consent (see ethics section).

#### 2.5.4. Study Sample and Demographic Information

Eight participants were recruited, all whom met the inclusion criteria (see Table 1 below for more information). More detailed profiles of individual participants have not been provided to maintain confidentiality.

*Table 1: Demographics of participants*

<b>Sex</b>	Five females, three males
<b>Age</b>	Ranged from 44-77 years
<b>Ethnicity</b>	Six British, one Irish, one Maltese
<b>Neurodegenerative condition</b>	Four PD, two MS, one MSA, one myotonic dystrophy
<b>Time since diagnosis (years)</b>	2-24 years

## **2.6. Ethical Considerations**

### 2.6.1. Ethical Approval

Ethical approval for the study was granted by the University of East London's (UEL) Ethics Committee, the relevant NHS Research Ethics Committee and the NHS Health Research Authority (see Appendix D).

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<sup>2</sup> As most neuropsychological tests are not appropriate for use cross culturally, any assessment on a person who cannot speak English would rely on a limited selection of tests, and subsequently it is likely their experience of testing would be very different.

### 2.6.2. Informed Consent

Informed consent was obtained from each participant prior to conducting the interview. This was achieved by providing potential participants with an information sheet and offering them the opportunity to ask questions about the study prior to signing the consent form (see Appendix E). To ensure participants did not feel pressured to take part, the information sheet and clinical psychologists initially approaching participants highlighted that participation was voluntary, independent of the service and would not affect their current or future care.

Due to the nature of neurodegenerative conditions, clients who lacked capacity to consent due to the severity of their condition, were unfortunately not invited to participate. To not unnecessarily exclude participants with cognitive deficits, the information sheet and consent form were, as much as possible, kept short, simple and free of jargon. Adaptions to the consent procedure were offered to participants, such as reading the information sheet to participants or re-visiting consent on multiple occasions to ensure a desire to participate was consistently conveyed across research encounters (Nygard, 2006).

### 2.6.3. Right to Withdraw

Participants could withdraw all their data up until the point of data analysis (one week after interview). After this, data may have been included in data analysis, so participants were offered the opportunity to review accuracy of transcripts or request direct extracts from transcripts not be included in the final report (as recommended in Smith et al., 2009)

### 2.6.4. Confidentiality and Anonymity

Anonymity was guaranteed as names and identifying features were altered in transcripts, extracts and resulting publications, and participants were assigned an identification number, of which I had sole knowledge. Participant's identification numbers were stored securely, alongside consent forms and participant record forms, in a locked filing cabinet at UEL. These were kept separately from audio recordings and transcribed material, which were stored electronically on a password-protected computer. I was responsible for transcribing the interviews

and transcripts were accessible only to myself, my academic supervisor and examiners. Audio-recordings and consent forms will be destroyed following examination of the thesis. Transcripts and data analysis output will be kept securely for a five-year period after the research submission, after this time they will be destroyed in accordance with the Data Protection Act (1998).

Participants were informed about confidentiality and its limits, including that if there were any concerns about participant's safety, confidentiality would be broken to consult with the clinical supervisor and where possible would be discussed with the participant beforehand. The thesis will be shared with the community neuropsychology service from which participants were recruited, so to reduce the possibility that extracts may be identifiable by readers from within the service, extracts were selected carefully. On the contrary, participants may wish to be openly identified within an academic forum, however this was discouraged to protect their own future anonymity and the anonymity of other participants.

#### 2.6.5. Risks and Benefits

It was not anticipated the study would cause harm to participants, however if participants became distressed during the interview, they were reminded their participation was voluntary and they were free to take a break, reschedule or withdraw from the study at any time without needing to provide a reason. At the end of each interview, time was allocated for debriefing and participants were offered contact details for supporting agencies should they wish to seek further support (see Appendix F). The clinical supervisor from the community neuropsychology service was informed if participants had shown signs of distress during the interview. I attended regular supervision with the clinical supervisor to help manage feelings that arose from distressing interview material to prevent 'researcher fatigue' (Dickson-Swift, James, Kippen & Liamputtong, 2007).

There were potential benefits to taking part in the study, including an opportunity to reflect on past experiences which may be therapeutic (Birch & Miller, 2000) and to have their voices heard which could help others in their position in the future. A small financial incentive (£10 Love2Shop voucher) was offered, plus travel costs of up to £5 were reimbursed. This communicated to participants that

their time was valued and reduced power imbalances, whilst not risking undue inducement (National Research Ethics Advisors' Panel, 2014).

## **2.7. Data Collection**

### **2.7.1. Semi-structured Interviews**

A semi-structured interview schedule was developed (see Appendix G) based on previous research (Owen, 2012) and relevant guidance (Smith et al., 2009) which recommended interviews as the best way to collect data for an IPA study (Smith & Osborn, 2007). The schedule acted as a guide, encouraging participants to recollect, talk in-depth and immerse themselves in their experience, whilst allowing me flexibility to modify responses and follow up interesting issues that emerged. To avoid interrupting the flow of conversation, notes of key points to follow up were made (using participants own words where possible), however notes were kept to a minimum so as not to limit eye contact, disturb non-verbal communication or in-depth listening (Mertens, 2005). The interview schedule consisted of a relatively small number of open-ended questions and avoided hidden assumptions that may have led participants towards certain answers (Pietkiewicz & Smith, 2012). Verbal input was kept to a minimum, with more specific questions only asked to check understanding. The same interview schedule was used for each interview; however, the ordering or phrasing of questions was adapted depending on how participants were responding. I was alert to shifts in the interview dynamic, towards a more affective, specific or disclosing atmosphere, following which I would revisit earlier topics to allow them to be gone into in more depth (Smith et al., 2009).

### **2.7.2. Challenges and Strategies for Conducting Interviews**

Conducting qualitative research with individuals living with a neurodegenerative condition posed numerous unique challenges resulting from the disease process or side effects of treatment (LaDonna & Ravenek, 2014). I reflected that many people with neurodegenerative conditions experience cognitive deficits including attentional difficulties, slow information processing, word finding difficulties and fatigue, meaning they may struggle with open-ended questions (Paterson & Scott-Findlay, 2002). However, as noted by Holsteing and Gubrium (1995),

“participants competence as interviewees is determined not as the ability to recount the details of their experience but, the way in which they organise the meanings they convey” (p.19), therefore with careful consideration and flexibility, they can make important contributions to research. In addition, previous research highlights how IPA can be utilised with groups who may be considered unable to provide a ‘rich’ account, such as with children (Conniff, 2008), or high-functioning individuals with Autistic Spectrum Disorder (Williams, 2004).

Smith et al. (2009) suggest an IPA interview schedule for an articulate adult contain 6-10 open questions with prompts, to generate between 45-90 minutes of conversation. It is recommended this number be reduced for people with possible cognitive difficulties (LaDonna & Ravenek, 2014; Paterson & Scott-Findlay, 2002), hence I decided to include four main questions, with numerous prompts to be used only if needed (many of which were different ways of asking the same question). Additional strategies employed were;

- being flexible about time of day,
- orientating participants to the neuropsychological assessment (i.e. the pen and paper tests you underwent that assessed your thinking skills)
- asking the most important questions towards the beginning,
- asking one question at a time and repeating if necessary,
- following the pace of the participant,
- minimising distractions,
- interviewing over multiple sessions if needed,
- allowing participants to go ‘off-topic’ for a few minutes before steering the conversation back to information relevant to the topic under study. Whilst this strategy could be critiqued for letting the interview schedule drive analysis (Smith et al., 2009), it was often a necessary and valuable strategy to gently guide participants back to the topic.

For participants with movement disorders, I was mindful that as a relatively inexperienced researcher in this field, involuntary movements may prove distracting. To ensure participants were as comfortable as possible, I provided a stationary chair and encouraged participants to let me know if they were unable to sit or stand for prolonged periods. For participants with poor voice volume

and/or quality and to minimise noises on the recording which may result from participants unintentionally hitting the surface where the recorder is positioned, two high quality digital recorders were placed thoughtfully during the interview (LaDonna & Ravenek, 2014). Furthermore, some individuals with PD may experience ‘masked face’ or loss of facial expression which provides important non-verbal cues in social interactions. To facilitate mutual understanding and empathy I often asked, “How does this make you feel?” to overcome difficulties related to reduced non-verbal communication (LaDonna & Ravenek, 2014).

### 2.7.3. Interview Focus

The interview schedule consisted of four parts;

**1. Participants were asked to tell me what they remembered about the neuropsychological assessment they underwent.** This was to introduce the topic and find out about their experience of being assessed, including their understanding of the purpose of the assessment.

**2. Participants were asked to tell me their experience of being assessed.** This was to find out how they viewed the experience, including the experience of the assessment environment and assessor, how it made them feel and whether certain parts were particularly memorable.

**3. Participants were asked about the feedback of results from the assessment.** This was to explore how feedback was delivered, the implications of results and how this made them feel.

**4. Participants were asked about the outcome of the assessment.** This was to determine whether they found the assessment useful or meaningful and whether anything had changed as a result.

### 2.7.4. Interview Process

All interviews took place in a quiet confidential room at either the community neuropsychology service, the university site or the participant’s home, with the appropriate lone-working policies followed. Prior to the interview commencing, the information sheet was revisited and participants were given the opportunity to ask questions, before signing the consent form and completing the participant record form to collect demographic information (see Appendix H). Throughout, I strived to establish rapport with participants, drawing on my experience as a



clinician, providing reassurance about what was required and listening empathetically to allow them to feel comfortable and relaxed.

Interviews were expected to last 40-60 minutes, which is ample for collection of sufficiently detailed data (Smith et al., 2009). Interviews were audio-recorded, with participants talking for an average of 58 minutes. Following the interview, participants were given the opportunity to raise concerns and reflect on the interview experience (Meyer, 1998). At this point, to reduce the power differential between myself and the participant, I welcomed feedback about how I could improve the interview. Lastly, participants were offered the option to receive a summary of findings from the study following its completion. None of the participants became distressed in the study.

## **2.8. Data Analysis**

### **2.8.1. Memo Writing**

Immediately after each interview, I recorded notable themes and reflected on my initial observations of the participant, context and setting of the interview. As a novice interviewer, I continually evaluated my interviewing style as part of an iterative process to refine my technique.

### **2.8.2. Transcription**

Interviews were transcribed verbatim, using a simple transcription scheme (adapted from Bannister et al., 2011; see Appendix I).

### **2.8.3. Analysis**

The data was analysed using IPA, following guidelines described by Smith et al., (2009) and Smith and Osborn (2007). The first stage of analysis involved reading and re-reading transcripts, noting initial points of interest, connections, contradictions and preliminary interpretations relating to the research question in the right-hand column. Subsequently transcripts were re-visited in a systematic manner to create a deep and rich level of analysis and inferences were made about the nature, meaning and context of participant's experience. Exploratory comments remarked upon descriptions (keywords, phrases, explanations, figures

of speech and emotional responses), linguistics (pronouns, pauses, laughter, repetition, tone, fluency and metaphors) and conceptualisations (overarching interpretations, 'meta' views).

The second stage involved identifying and labelling emerging themes, recording them in the left-hand column (see Appendix J for worked example). Where possible participants own words were used, in keeping with the phenomenological nature of IPA. These themes guided readings of subsequent transcripts, although I continually looked for new or contradictory themes and referred to the right-hand column to ensure my interpretations were grounded in participant's accounts (Willig, 2008).

In the third stage, connections were made between emerging themes, with some themes acting as magnets pulling others towards them, in a bid to facilitate sense-making. As Smith et al. (2009) suggests, related themes were clustered using electronic cut and paste exercises over several weeks to group them into potential subordinate and super-ordinate themes.

Finally, following the analysis of each interview individually, a similar process was followed to amalgamate themes across interviews. This process involved continually checking interpretations and resulted in a list of subordinate and super-ordinate themes (Willig, 2008; see Appendix K). Key quotations to illustrate each theme has been expanded into a narrative account to form the basis of the Results chapter.

## **2.9. Reflexivity**

In qualitative research, it is important for researchers to be openly reflexive about preconceptions, biases or assumptions they hold about a topic, as this can increase a studies rigour (Polgar & Thomas, 1991). According to Willig (2008), there are at least two types of reflexivity; personal reflexivity and epistemological reflexivity. Personal reflexivity is an awareness of how the research process is affected by the researchers own professional and personal, cultural and political values, beliefs and experiences. Epistemological reflexivity is an awareness of

how a researcher's ontological expectations (what they anticipate capturing during the research) affects the research process (Robson, 2011).

As Malterud (2001) states "a researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and then framing and communication of conclusions" (p.483-84). Whilst it is impossible to eliminate one's perspective entirely, being self-reflective allows researchers to acknowledge and 'bracket off' pre-conceptions that influence the interpretation of data. To optimise reflexivity and transparency, a journal was used to record personal reflections (Ortlipp, 2008; Vicary, Young & Hicks, 2016).

### 2.9.1. Personal and Professional Position

I am a 28-year-old white British female, who grew up in a largely white British, working/middle class outer London suburb. My previous experiences working in psychology for 4 years, combined with my clinical psychology training at UEL, have undoubtedly influenced my personal values and led me to favour social constructionist and critical approaches in clinical practice and research. My own position in approaching this research is one of a critical realist; acknowledging the reality of individuals experience, whilst emphasising the importance of historical, social, political and cultural contexts in shaping how individual's experiences are constructed.

My keen interest in the process of neuropsychological assessment, developed prior to training, through my work in various settings, where I administered neuropsychological assessments. I was often struck by how differently each person experienced testing, and witnessed first-hand the various reactions during feedback sessions. Whether diagnostically driven or for functional assessment, I recall feedback sessions and subsequent reports being filled with jargon, sounding very medically orientated, meaning as a professional I was often placed in the position of 'expert'. I recall feeling frustrated as the lack of collaboration or support for clients and their families throughout the process, which had a lasting impact on me.

As my training progressed, I noticed a disparity between my social constructionist approach and sometimes how neuropsychological assessments were used in a concrete or arbitrary way. Since then I have been inspired by fellow professionals who have skilfully combined neuropsychological assessment with a more collaborative systemic approach. I am therefore approaching this research with the belief that neuropsychological assessment can be a useful and meaningful tool, but that it should be done with consent (not done to), and that it may not be useful for everyone. My position is one of curiosity; what is the experience of neuropsychological assessment - if it is useful, why and how so, and if it is not useful, why and what could help?

Following a discussion with my supervisor about my area of interest, he pointed to the paucity of qualitative research in this area, especially with people living with neurodegenerative conditions. Through my experience, I have been committed to giving voice to marginalised groups and I was surprised at the lack of studies focussing on the experience of those living with a neurodegenerative condition. I have relatively limited experience in working with people with neurodegenerative conditions and in some respects, this has allowed me to stay close to individual's experience without my own views influencing my interpretations (although inevitably I will hold assumptions on related discourses e.g. cognitive abilities, disease, death).

### 3. RESULTS

#### 3.1. Overview

This chapter outlines the four superordinate and sixteen subordinate themes that emerged from analysis, reflecting the eight participant's described experiences of neuropsychological assessment. In the following narrative account, each theme is presented and explored in detail, illustrated using verbatim extracts from the interview transcripts of each participant. Within each theme individual participant's experience will be discussed, including any commonalities and differences. Themes are neither exclusive nor all-encompassing, so whilst ideas relating to one theme may resonate with other themes, they cannot cover every possible aspect of each person's experience. It is worth noting that the themes represent one possible account of participant's lived experience, as seen through *my* lens as a researcher. Other researchers may have focused on different aspects of the accounts; hence this account offers a personal and subjective interpretation.

Occasionally, the verbatim extracts have been minimally altered to improve readability. Where phrases are truncated to omit pauses in speech or portions of the text without altering the meaning, this is indicated using ellipsis (...), and where the subject of an extract is absent, parenthesis have been added for reference in square brackets. Each participant has been assigned a pseudonym and participant's specific diagnoses have been omitted to maintain anonymity. Each extract is referenced to the participant and corresponding line number on the transcript.

#### 3.2. Superordinate and Subordinate Themes

The superordinate and subordinate themes that emerged from analysis are summarised in Table 2. A table illustrating the recurrence of each theme within participant's accounts is provided in Appendix L.

*Table 2: Summary of themes representing people with neurodegenerative condition's experience of neuropsychological assessment*

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
<b>Expectations of assessment</b>	<b>Deciding to undergo assessment</b> <b>To measure cognitive decline</b> <b>Anticipating understanding and coping advice</b>
<b>Relationship with clinician</b>	<b>Positive clinician qualities supported coping</b> <b>Familiarity and trust</b> <b>Expertise and power</b>
<b>Experience during testing</b>	<b>Subjective awareness of performance</b> <b>Emotional response to testing</b> <b>Coping with testing</b> <b>Intense and prolonged</b> <b>Importance of environment</b>
<b>Outcome of assessment</b>	<b>Communication of results</b> <b>Meaning of results</b> <b>Emotional impact of results</b> <b>Coping strategies provided power and control</b> <b>Future implications</b>

### 3.3. Expectations of Assessment

This theme concerns participant's beliefs about the nature and purpose of assessment. Overall, despite trepidation in deciding to undergo the assessment, participants described an overriding desire to measure possible cognitive difficulties, and to seek explanations and advice regarding coping with deficits.

#### 3.3.1. Deciding to Undergo Assessment

In deciding whether to undergo assessment, participants described a sense of trepidation as they anticipated possible outcomes. In the following extract, Arthur suggests he 'might not like' the outcome of the assessment:

*I knew I was going to be on some sort of learning journey, I might not like it, but I'll be on a learning journey, I was geared up for that. (Arthur:334-337)*

In this extract, Arthur appears to value the possibility of learning, despite the potential for a negative outcome, and uses the metaphor of travelling, as if the assessment will move him forward to a worthier 'destination'. Unable to stop the momentum started by his request, he describes mentally preparing himself to face the consequences, implying a strong motivation or pressure to complete the assessment. Lisa also describes her fear:

*You think "oh goodness this might open a can of worms". (Lisa:384-385)*

In using this idiom, Lisa articulates concern that her attempt to gain reassurance regarding her cognitive abilities, may result in new unexpected problems. Despite apprehension, participants sensed they 'should' do the assessment:

*I didn't have to do it but, I knew that I ought to do it. (Lisa:754-757)*

*It's got to be done, and if you don't ask the questions, how are you going to get answers. (Jean:395-397)*

These extracts illustrated participant's apparent moral judgement of neuropsychological assessment as the 'right' thing to do. Indeed, Jean notes she would not benefit from answers, were it not for completing the tests. Hence participants seemed to experience an internal struggle weighing up the potential unwanted outcomes against a desire to undergo the assessment.

This may have been exacerbated by the medical context, where dominant discourses describe tests being unpleasant, yet necessary (e.g. blood test). Hence, participants also appeared to experience expectation to consent from external sources. As Arthur admits:

*What I wanted to do, and I was told to do, is be able to see if my condition is deteriorating. (Arthur:5-7)*

Whilst Arthur's own desire to complete the assessment is clear, he acknowledges he was 'told to do' so, suggesting participants experienced an expectation not only from themselves, but directly stated by others, (although in this instance we remain unclear who). This left me questioning whether participants felt able to decline a neuropsychological assessment if offered.

### 3.3.2. To Measure Cognitive Decline

Most participants spoke about undergoing assessment to discover possible cognitive deficits, and measure potential progression of their condition. In the following extract, Arthur uses an analogy with his previous occupational role, to describe his desire to 'actually measure...rather than speculate':

*What I wanted to do...is be able to see if my condition is deteriorating or is static or is improving, so what I wanted, and this is typical management, you know, I want something I can actually measure. (Arthur:5-10)*

Thus, it appears Arthur anticipated the neuropsychological assessment would be similar to his management role which could be broadly defined as 'controlling things or people'. This concept of control is further asserted, as the desire to record a baseline measurement seems to be *his* request. Arthur's description of



potentially measuring improvement, seems to suggest he is keeping a positive outlook. In contrast, some participants, aware of difficulties with cognitive ability, saw the assessment as a chance to quantify progression:

*I was quite interested to find out how much of my memory was affected, cos I do know that my memory was affected by the [neurodegenerative condition]. (Sheila:11-14)*

*It's interesting to know...how things are developing with your brain, you know you become aware like with something like [a neurodegenerative condition] that things are starting to deteriorate, and you know it's interesting then to be able to maybe get proof of, what you might be experiencing in life. (Helen:209-214)*

Early cognitive symptoms can often be subtle, even significant cognitive impairments may not be immediately apparent and can be considered a 'hidden' disability, hence the concept of 'proof' was clearly important for Helen. The description suggests the assessment would confirm the existence of cognitive difficulties as 'fact', helping to explain associated impacts on daily functioning, proving she wasn't "lazy"(322), both to herself and others. Other participants corroborated the difficulty in judging their own possible cognitive decline:

*Of course, that's the one thing you can't see is your head, if you know what I mean. (Lisa:152-154)*

*Well, it's easy to see that it's difficult for me to get in and out of this chair, it's obvious that I haven't got the strength and the mobility I had, but like I said to you, in terms of my thinking, it's quite difficult to measure. (Stephen:475-479)*

Stephen, in comparing his cognitive ability to his physical deficits, vividly captures the relative obscurity of cognitive deficits. Thus, participants expected the assessment to help make the invisible, visible. Stephen goes on to note:

*The joint aim of [the assessment] was just seeing where I was from a cognitive point of view, cos that's one thing you can probably measure quite accurately. (Stephen:111-114)*

Whilst this appears to directly contradict Stephen's earlier statement, on closer inspection, his use of the word 'you' in the latter extract, suggests whilst *he* struggled to measure his own cognitive ability, the clinician using a neuropsychological assessment could provide an accurate measure. The participants differed in their views about who the measurement was for, with Stephen acknowledging "*in my mind, it was really selfish*"(64), whereas Jean comments:

*Basically, because I'd been diagnosed with [a neurodegenerative condition] and they wanted, I suppose, to find out if it was getting any worse. (Jean:19-22)*

Whilst Stephen seemingly says that his experience of the assessment was solely for his benefit, Jean interestingly remarked it was 'they' who would benefit. It appeared for her the tests represented a tool utilised by powerful experts to ascertain her possible decline, allowing professionals to find out how to help her.

### 3.3.3. Anticipating Understanding and Coping Advice

The participants voiced a hope that the assessment would provide explanations regarding cognitive deficits, with many participants expressing a desire for support in coping with their difficulties. Participants spoke about their desire to find answers, to alleviate speculation and empower them with knowledge:

*Well I just thought that there was something going wrong in my mind, and I wanted my neurologist to refer me to somebody who could explain what was going on in my mind. (Wendy:346-349)*

*I need to understand what was going on. (Arthur:14-15)*

Some were seeking answers to specific questions, including Lisa who, in light of her diagnosis, queried the cause of her forgetting:

*I've been reading about symptoms of [the neurodegenerative condition], and I was asking [the psychologist] "how, how would I, how do you know whether it's a cognitive decline or whether you've just got a million things on your mind?" (Lisa:74-78)*

In this extract, it is clear Lisa made her own attempts to acquire knowledge, but in the process, has been left with questions which she hoped the assessment would answer. Others desperately sought strategies to help with their condition:

*I'm getting to the stage where I'm getting desperate... you know what's coming, but you'll do anything to make it go away. (Stephen:635-639)*

*You can put it into a strategy...then we can start seeing if there's anything we can do which will slow it, slow the [neurodegenerative condition] and help me understand what I need to do. (Arthur:76-80)*

Arthur's desire to act and possibly control the progression of his condition is palpable. The use of 'need' conveys a sense of urgent requirement, as if he is preparing for battle, refusing to give in. On one hand, Arthur suggests the assessment will help him understand the necessary course of action where he has previously failed, yet on the other hand, his use of the word 'if', nods to the fact his search might be futile.

### **3.4. Relationship with Clinician**

This theme captures the importance of the quality of the clinician-patient relationship, and the powerful influence this had over participant's experience. For some, the nature of the encounter with clinicians was essential to their experience, enabling them to cope with the anxieties of testing, and creating a trusting space to discuss difficulties.

#### 3.4.1. Positive Clinician Qualities Supported Coping

Most participants experienced clinicians as friendly, collaborative and person-centred, allowing them to feel genuinely listened to and put at ease:

*I think he was a very good, quite conscientious psychologist...he would listen to you, he'd listen to your points of view. (Helen:441-445)*

*She was quite sympathetic, and she was good with communicating, and she made me feel at ease. (Sheila:70-72)*

Helen highlights the importance of her views being listened to and heard, suggesting she appreciated the collaborative nature of the relationship. For Sheila it was the clinician's emotional warmth that allowed her to feel at ease. Wendy describes her most recent experience as "Rolls Royce"(274), likening her experience to a brand known for luxury. She explains the clinician's positive qualities by comparing her experience with a previous clinician:

*I was more patient with him, because he treated me with more openness generally, so I felt I could actually accept what he was saying, because I felt he listened to me in a very special way. (Wendy:575-583)*

Wendy notes the circularity and reciprocity of the relationship, stating how the clinician's behaviours impacted her and vice versa (e.g. the clinician's openness allowed her patience), resulting in her being able to 'hear' and accept recommendations, rather than feel defensive. In addition, Wendy states the clinician listened in a 'very special way', indicating an active listening beyond what she had experienced in other relationships. Graham remarks on the non-verbal qualities he valued:

*[Her] calm clear voice and she smiles, she smiles sometimes [laughter], all positive things that you would pick out in a human being's facial expression or whatever, she has them. (Graham:358-362)*

Most participants identified qualities of the clinician, as helping them cope with the emotional demands of assessment:

*They tried to keep you at, make you at ease, which is an important factor me, because I get a bit uptight otherwise, bit worried. (Jean:173-175)*

*She was a very calming influence. (Jean:181-182)*

For the majority, the clinician's emotional support seemed to bolster participants against more threatening aspects of testing, normalising 'failure', reducing anxiety and minimising distress. Jean noted her appreciation for receiving praise from the clinician:

*Sounds silly cos I'm an adult, but you know, we all need praise sometime. (Jean:348-350)*

Jean initially dismisses her desire, sensing as an adult she is not expected to require praise, before subsequently normalising it. However, Arthur appears to interpret the clinician's comments as questioning his resilience:

*[The clinician] consistently sort of just checked me out say "are you feeling okay?", "are you comfortable?" etc., which is great, but I think I'm resilient enough. (Arthur:440-447)*

Whilst Arthur verbalises the support as 'great', he implies it was not necessary, with the use of 'consistently' providing a clue that he found it excessive.

#### 3.4.2. Familiarity and Trust

Many participants described a preference for a familiar clinician, enabling them to be aware of participant's background and fears:

*I suppose one of my big fears is that I that I lose some sort of mental function, which she'd probably been aware of because I'd spoken to her about a number of things...I don't know whether that particular*

*psychologist was mindful of my concerns, and made a bit of an extra effort to explain more. (Lisa:315-321)*

Thus, from Lisa's perspective, familiarity allowed an individualised approach, based on her needs. In addition, familiarity allowed participants to build trust prior to the assessment:

*I've known [the psychologist] a while, so I trust what she says. Maybe if I'd only met her once or twice, or it was [another psychologist]...I might have asked a few more questions. (Stephen:421-425)*

*The good thing was [the psychologist] asking, someone you got to know, asking you these questions. If it was a complete stranger asking, you would've been a bit-, might not of answered them as truthfully or wouldn't have felt as comfortable answering the questions. (Graham:311-319)*

The descriptions suggest for Stephen trust is earned over time, through questioning the clinician, perhaps to see if they produce satisfying, trustworthy answers. Graham suggests if the clinician was unknown, he would have censored answers, preventing a mutual understanding and exchange of information. It seems a strong therapeutic relationship and subsequent trust, reduced anxiety and gave participants a sense of ease. The presence of trust had various meanings to participants:

*That's [the feedback] what I wanted to hear, but I knew if it wasn't, if that wasn't the case, [the psychologist] would have said well "you're just a thicko" [laughter]. (Stephen:440-443)*

For Stephen, trust amounted to honesty, implying an unfamiliar clinician may not have felt confident breaking bad news, instead protecting his feelings. However, Stephen imitates the news he fears a trustworthy clinician delivering ("you're just a thicko"), perhaps indicating he fears the loss of a previously existing identity in which he was cognitively able. For Graham, trust amounted to the clinician having good intentions:

*I was just glad I found out with someone (.) who was doing it for a good reason, rather than someone who would just be trying to take advantage of you like, like someone who might be trying to con you or something out in the street, and finding out you weren't so good at something that way [laughter], rather than someone just in a friendly atmosphere just pointing these things out to you. (Graham:466-475)*

Thus, Graham felt reassured the clinician would not exploit possible vulnerabilities or wrongly benefit from discovered weaknesses. In contrast, when directly questioned about the possibility of testing with an unfamiliar clinician, Lisa stated:

*If it'd been another psychologist, that did all the tests, that wouldn't have concerned me, because I'd been briefed quite well about what was going to be tested and why. (Lisa:340-343)*

Thus, Lisa negates the importance of familiarity, on the basis she had been well prepared by a familiar clinician.

#### 3.4.3. Expertise and Power

Most participants valued the clinician as an expert and “professional”(Helen: 471), regardless of their status as a qualified or trainee clinical psychologist. In the following extract, Lisa, who was assessed by a trainee, acknowledges the significance of the level of training held by the clinician:

*Having somebody that's qualified reading it, obviously makes a massive difference, where as I might've got the wrong end of the stick or something, but there was no chance of that because she was so helpful. (Lisa:504-508)*

Thus, the clinician's competence to interpret results, minimised the risk of Lisa misinterpreting, which had the potential to impact on her emotional wellbeing. Stephen describes the clinician's actions as 'wise':

*[The psychologist] sort of very wisely I think, decided to bring it to an end.  
(Stephen:16-18)*

Thus, Stephen suggests the clinician's capability of good judgement, yet also highlights the power held by the clinician to direct the session. Several other participants expressed an awareness for the power held by clinicians. Wendy recalled the clinician had power to influence those who could refer, stating the clinician *"told my GP to refer me on to a neuro-ophthalmologist"* (540-541). Thus, power enabled clinicians to demand and influence behaviour of others. Following these extracts, it is possible to assume there is a power imbalance between participants and clinicians, however some participants articulated occasions where power was shared between the clinician and participant (further discussed in 'communication of results').

### **3.5. Experience During Testing**

This theme captures how participants experienced and made sense of testing. The absence of feedback during testing, means participants often appraised their own performance, resulting in sense of uncertainty, fear, frustration and disappointment. To regulate their emotional response, participants used various coping strategies, including focusing on the positive, drawing on previous experience, minimising, normalising, avoiding and denial. In addition, participants spoke about the intensity of their experience during testing and the importance of the assessment environment.

#### **3.5.1. Subjective Awareness of Performance**

All participants were sensitive to their performance during testing, with some recalling a subjective sense of success:

*I think I got it exactly right, I was pretty impr-, that's probably why I remember it so well cos I done it so well [laughter]. (Graham:7-10)*



*I was enjoying it, like I said in a perverse way, and I knew, I thought I was doing quite well. (Stephen:239-240)*

With Graham introducing his sense of success almost immediately in the interview, it is clear it was particularly salient. His commentary and laughter suggests the perceived success was unexpected, therefore emotionally significant. Especially within the context of his neurodegenerative condition, in which he stands to lose his cognitive ability, his success represented a confirmation of retained ability. Most participant's accounts were peppered with self-doubt, yet Graham asserts his certainty stating he got it 'exactly right'. He appears to tail off expressing how 'impressed' he felt at his performance, perhaps not wanting to sound overly self-assured. Stephen links his enjoyment to his perceived skill, although his use of 'perverse' acknowledges testing is not what most people would expect to enjoy. He explains:

*I got into some dusty corners of my mind actually, it was nice to dust some off, yea cos, I've had that same job for twelve years and I'm get a bit of a routine, so it's nice to sort of get outside your comfort zone, so I did really enjoy it. (Stephen:615-620)*

Thus, Stephen felt the testing allowed him to use cognitive abilities he wasn't able to routinely, as if the practice would be beneficial to optimise his abilities. His metaphor of 'dust' seems to reflect a cognitive foggy, with the experience of testing indicative of a 'spring clean'. Indeed, most participants, relying on their subjective appraisal, assumed they had performed poorly (regardless of the eventual outcome):

*It weren't sticking in my head, it was that obvious that there was a problem. (Graham:21-23)*

*I realised I've still fallen down at things that in the past I wouldn't have found difficult to do. (Wendy:501-503)*

Thus, perceived 'failure', was experienced as highlighting 'problems', exposing lost abilities. For participants expecting cognitive decline, confirmation bias may have resulted in a tendency to interpret poor performance (rightly or wrongly) as confirming deterioration. Participants appraised their performance based on various clues. Graham notes it was 'that obvious', suggesting in his eyes, his poor performance felt so apparent it could not be mistaken. Wendy uses comparison to her previous abilities, as measured by daily functioning and previous neuropsychological assessment, although her use of 'still' implies she was already aware of potential decline. For others, the appraisal of their performance was based on intuition:

*I knew myself I'd got them wrong, no one had to tell me I'd got them wrong. (Jean:80-82)*

This suggests, it was not subtle signals given by the clinician, but instead intuition that was relied upon for evidence of performance. Although, as Lisa admits "*it's hard to tell when you're doing the test*"(572-573). Thus, whilst it was clear participants endeavoured to make sense of their performance, it was difficult, especially whilst testing, to gain an accurate sense of performance. As Stephen vividly captures:

*In the middle of all that, you're sort of thinking, "if I was not-, if I didn't have this diagnosis would I find this difficult or not?" and actually, I'm still not quite sure what the answer is because, I think it's difficult for me, because I'm thinking "is that because I'm [this age] or is it because I've got [a neurodegenerative condition], or could I never have answered that question?", so you've got all that going on at the same time. (Stephen:30-39)*

Stephen's narrative suggests internal rumination simultaneously occurring throughout testing, where he questions the cause of his perceived struggling. Interestingly, towards the beginning of the extract, Stephen tails off verbalising 'if I was not-' perhaps suggesting he is hesitant to name the reality of what has happened to him. Stephen continues:

*To be honest with you it was a double-edged sword because sometimes I was “yes:::” and other times I was “oh s\*\*t I just can’t do it”, and again you’re thinking “why is it-, could I ever have done that?” (Stephen:66-70)*

Thus, Stephen questions his current performance in relation to his past-self, with his use of expletives suggestive of his frustrated emotional state.

### 3.5.2. Emotional Response to Testing

With participants seemingly aware of their performance to some degree (albeit not necessarily perceived accurately), it follows that participants reported testing as an emotionally intense experience, with highlighted inabilities, resulting in feelings of loss, fear, stress, frustration, disappointment, self-doubt, low mood and low self-esteem:

*I was frustrated that I got in a muddle with my memory, my thoughts had kind of messed it up. (Jean:54-56)*

*I got really, really frustrated and I think that showed. (Stephen:11-12)*

*I was scared that I couldn’t remember things. (Sheila:63-64)*

*I was going to get stressed about it, cos it’s not-, I’m not st-, handling it very well. (Arthur:154-156)*

*I was a bit disappointed in myself for getting something wrong, cos I thought it was quite basic test. (Lisa:185-188)*

In these extracts, Stephen’s emphasis of ‘really’ suggests the intensity of his frustration, and possible embarrassment the clinician witnessed it. Arthur appears hesitant in naming his difficulty ‘handling’ the test, and was reluctant to do so throughout the interview, perhaps to protect his own self-esteem (further discussed in ‘coping with testing’). Lisa finds herself judging the difficulty of the test, measuring herself against her own high standard, which she later names as

her being a “perfectionist”(604). Below, Jean highlights her emotional response to perceived ‘failure’:

*I’ve always beat myself up, in my lifetime, when I don’t feel quite so happy about where I am...I’ve always tried to keep up, you know, I mean I wasn’t born in a high place in society. (Jean:99-107)*

There are several important issues to note in this brief extract. Jean uses a metaphor of physical violence, to show her self-punishing stance towards her own ‘failure’ during testing. This highlights how participant’s histories will inevitably affect how they respond to testing. Jean subsequently points to ‘trying to keep up’, implying she felt behind during testing, which she compares, unprompted, to her place in society where she too perhaps felt ‘behind’. Several participants described their experience of testing as a series of highs and lows. For Jean this reflected her perceived performance:

*I felt quite uplifted when I got the questions correct, but I felt quite let down when I got them wrong. (Jean:78-80)*

Graham shared a similar experience:

*When I was getting things right like, I thought “you ain’t that bad, you have-, there is something that’s still working inside properly”. (Graham:59-62)*

*[If] I weren’t doing them as well, it did make me “oh what’s wrong with you, what’s wrong with you”. (Graham:463-465)*

These extracts highlight the turbulent nature of Graham’s emotional reactions, alternating from feeling reassured with regards to retaining his faculties, to frustrated for ‘failing’ a test he ‘should’ be able to complete. The use of ‘wrong’, suggests he is not only incorrect, but judges and insults himself for the perceived ‘failure’. Yet unable to change his performance, he is left to cope with the evoked emotions.

### 3.5.3. Coping with Testing

To cope with demands of testing, many participants utilised a variety of self-protective coping strategies to alleviate distress. Participants ability to cope did not appear to link directly to their performance, but rather their ability to manage the experience, maintaining a positive sense of self. Stephen spoke about his attempt to identify practical strategies:

*It's looking for the key to the puzzle isn't it, and you find it and you're okay, or finding some way of remembering...once you do that and you've got a, you've found a good way of doing it, you get a bit more confident, especially if it's worked for you, I'll use that next time I have to do a similar question. (Stephen:283-295)*

Thus, Stephen uses a 'key' metaphor to describe his strategies, suggesting once identified, they 'opened' his ability, allowing him to build confidence throughout testing. Although, he notes, well-practiced strategies were not always successful, hence the process required flexibility, demanding participants to adopt new ways of coping. As well as practical strategies, participants talked about trying to utilise strategies to cope with the emotional demands, for instance remaining task-focused, concentrating on positive aspects of performance and localising areas of weakness:

*I just thought "alright, them ones you can't do, but the ones you can do, like concentrate on them and make them things better or as good as they can be". (Graham:65-68)*

*I'd got something wrong, when I say wrong it was one bit. (Lisa:593-595)*

Here, Graham urges himself not to dwell on items he found difficult, instead encouraging himself to focus his attention and energy on tests he is most likely to succeed on. Lisa emphasises the word 'one', minimising her perceived 'failure', later re-framing it as a "*minor blip*"(442) and "*mistake*"(447). Some participants normalised negative experiences of testing, for instance Arthur normalised his anxiety:

*Whatever test you're taking, whatever environment, there's a level of sort of anxiety to it, cos you want to be probably seen to be a good person, you want to meet the standard, you don't want people to talk about you in derogatory terms. (Arthur:657-662)*

The description suggests Arthur makes sense of his anxiety as stemming from a fear of stigma and judgement from others. Others utilised previous experience, both in life and previous neuropsychological assessments, to put the testing in perspective:

*I realised I've still fallen down at things, ...that was slightly distressing to me, but not really because I'd already experienced that. (Wendy:501-505)*

*I've had a lot of life in difficult places, so it didn't stress me at all. (Arthur:177-178)*

Thus, Wendy had been emotionally prepared for possible 'failure' by her previous assessment. In addition, Arthur suggests the testing paled in comparison to other life stressors. Furthermore, he previously talked about his high achieving career, during which he completed similar psychometric tests, reducing his fear of the assessment. Arthur approached the testing with a matter-of-fact attitude, attempting to resolve potential distress by discontinuing tasks he was 'failing':

*I tend to take the view on everything, if I can't do it and I will fail by my standard, then it's better to pull out of it. (Arthur:180-182)*

Thus, faced with a threat to self-esteem, Arthur uses avoidance as a way of coping. Although traditionally seen as a less helpful strategy, in this instance it allowed Arthur to finish the testing, whilst preserving his capable sense of self. Similarly, several participants reported attempting denial, as Sheila admits:

*Yea, maybe...I didn't want to know (.) how bad I was. (Sheila:127-128)*

On reflection, Sheila acknowledges and articulates possible denial, yet the very nature of denial, means it may be possible to interpret from participants accounts rather than verbalised directly. In this extract, Arthur denies the testing was challenging:

*It was a test...was it a challenging test, not particularly. (Arthur:271-272)*

Yet elsewhere in his narrative, Arthur describes the test stresses him to the point of halting it, which seems to contradict the idea of the test not being challenging, hence denial may be serving to keep the unacceptable reality at bay. In fact, with the potential threat to self-esteem, Arthur appears so enraged as to suggest:

*That particular test, I think should be removed, but it's your call.  
(Arthur:157-159)*

Thus, perhaps Arthur not only desires to protect himself, but also others, yet he acknowledges the power lies in the hands of the clinician. In contrast, whilst most of the strategies had a beneficial impact on participants ability to cope, Stephen acknowledges his attempts to alleviate distress were not always successful:

*I was very grumpy that day, but I was just struggling, I couldn't-, I was trying to calm myself down and I was just winding myself up. (Stephen:84-87)*

Hence, Stephen, unable to soothe himself and worried he would “give a false account”(91) of his abilities, ultimately turns to the clinician for reassurance, emphasising the important of the clinician's role.

#### 3.5.4. Intense and Prolonged

Most participants spoke about the length of testing and it's intense and repetitive nature:

*There's a lot to get through. (Stephen:531)*

*Some of the things are repetitive, obviously they need to see what you can remember. (Sheila:4-6)*

*It was a two-hour appointment and I was wondering why it was so long. (Wendy:12-14)*

This experience was common in the interviews and in the case of Sheila and Wendy was introduced early in the interview highlighting the prominence of the issue. Whilst Sheila provides a potential reason for the repetitive nature of testing, Wendy felt she had not been prepared, and questioned the appointment length. The extracts provide a sense of testing as something to 'get through', a boring process, to be endured. Stephen comments he was grateful for the option to split testing across numerous sessions. Stephen highlights the intensity of testing compared to other healthcare appointments:

*A lot of people come round here to see me from [the service] it's always pleasurable... this was different...we've got the clock on, we've got a-, you can look at these for a minute and then I'll take them away, so it's it's quite comp-, you know the-the intense, so that the intensity of a series, an exam setting is obviously an intense thing isn't it. (Stephen:140-153)*

Thus, Stephen implies testing was not pleasurable, but intense. The change in pace and flow of his speech seems to reflect the fast-paced and relentless nature of the testing, and he ends the passage 'isn't it' perhaps inviting reassurance he is not alone. He later explains how the fast-pace of testing, alongside his internal "monologue"(161) and environmental distractions all added to the level of intensity. Helen mirrored this with her description of the time pressure she felt:

*There was less time, you know, you answered straight away...you had to do like, quite a few different tasks in a set time and see how you coped with that. (Helen:162-166)*



The description suggests Helen experienced a sense of urgency, aware her performance would be observed to see how she 'coped'. As well as pressure to focus, some participants noted the hard work and concentration required:

*The tests need some intense thinking in order to crack. (Stephen:167-169)*

The use of 'crack' implies the tests were problems to be solved, reflecting the considerable effort Stephen put in to discover the solution. Many participants commented some tests appeared deceptively easy, but had a hidden difficulty. Several participants spoke of how testing reminded them of being back at school:

*At the time, I felt like I was in a classroom, you know like I was at school basically.*

*I: Tell me more about that.*

*That's how I felt, I felt I was in school, like when I was a child. (Jean:74-78)*

Thus, whilst Jean doesn't explicitly name how she felt as a child, it could be interpreted she sensed a loss of control and power of adulthood. Indeed, participants reported it had been a long time since they underwent formal examination, hence the testing may be experienced as infantilising, denying them of their maturity. Alternatively, as Jean doesn't explicitly name feeling like a child as undesirable, perhaps she enjoyed relinquishing responsibility of adulthood during the testing.

### 3.5.5. Importance of Environment

Several participants talked about the importance of the assessment environment and its impact on the testing:

*I found it difficult to concentrate because there was things going on around me and I'm quite a sticky beak, you know what that is, nosey. (Jean:139-142)*

*That's probably the [neurodegenerative condition] where anything can distract you, so you know you should be concentrating, but you're having*

*this sort of monologue...as well as thinking: there's a spot on the wall, there's a fly; over there's a pigeon. (Stephen:52-58)*

In these extracts, both Jean and Stephen talk about the difficulty of navigating environmental distractors, yet interestingly Jean seemingly blames herself for being 'nosey', whilst Stephen partly blames his condition, hinting at the subjectivity of his experienced distractibility. Perhaps participants sensed they 'should' be able to manage distractors, hence weren't entitled to an uninterrupted environment. In fact, Stephen goes as far as to suggest it was his responsibility to reduce distractors:

*Could maybe put the blinds down or something, less distraction, but that's my problem...maybe it was a good environment...but maybe just to give thought to the environment, maybe even I could have sat with my back to the window, and it would've been one slight improvement. (Stephen:803-814)*

Certainly, in hindsight, Stephen had ideas about how to make the environment more comfortable. Another participant appreciated a comfortable, familiar environment, with limited distractions:

*No issues with regards to where the test was done, or you know, I had water and stuff like that, and I knew where the loo was and all that sort of stuff, so no absolutely (.) I think the environment was very nice. (Lisa:252-257)*

### **3.6. Outcome of Assessment**

The fourth and final theme captures how participants made sense of varied results (with some participants told they had no impairments, whilst others were informed of significant deficits). In addition, this theme will explore the emotional impact of results, the future implications, and how meaningful feedback empowered participants to cope and adjust.

### 3.6.1. Communication of Results

The participants spoke about helpful and unhelpful ways in which results were communicated. Prior to the assessment, some participants acknowledged they were unaware how cognitive abilities could be affected by their condition, yet following feedback, most participants felt they had been provided with a thorough explanation:

*She had all print outs and they explained with very simple diagrams...colour coded, and she made it simple so you could understand, and she explained it and left the folder with me. (Sheila:327-331)*

*She sort of briefed me at top-level say, you know, cos I'm not a psychologist, or medic, so she just sort of went through what it was, that was being...tested, and why. (Lisa:299-303)*

Thus, Sheila appreciated the comprehensible and diagrammatic feedback, which she could revisit as necessary, empowering her. Lisa notes the explanation was 'top-level', suggesting she felt provided with the highest level of explanation, although she mentions she is not a professional, emphasising the importance of an explanation appropriate to participant's level, without jargon. As Stephen recommends:

*It's worth bearing in mind that people suffering from my symptoms are sometimes not the sharpest tools in the toolbox, or not as sharp as they used to be, so an overall brief of what's gonna happen, what's happening, what's happened. There's an old saying – tell them what you're gonna tell them, tell them, tell them what you've told them, you can't go wrong with that. (Stephen:708-715)*

Hence, repetition and clear explanations enhanced participant's ability to understand, minimising the potential for participants to feel 'stupid'. Wendy notes the clinician made feedback "*comprehensible*"(575); hence she attributes her ability to comprehend, to the clinician's skill, who empowered her to understand.

Arthur picked up the clinician's hesitancy explaining results, leading him to question whether the clinician was "*buying time*"(592) to tell him bad news:

*[The clinician] was, I felt, very cautious about what she was going to say, and I felt, you know, is there something you don't want to tell me...if there is something you need to tell me, that's going to be unpleasant...just tell me, I can get on with my life. (Arthur:400-410)*

Arthur seems to say that the clinician may have been attempting to break bad news gently, to prevent him entering a "*crisis*"(623), but he desired directness and honesty. Participants emphasised the value of written feedback, with separate versions for themselves and professionals. As Helen explains:

*He wrote it up and sent me a copy of that, but that was more from a clinical point of view, so he then wrote it out in a layman's point of view [laughter] for me to be able to follow. (Helen:75-79)*

Helen's laughter potentially conceals her embarrassment regarding her difficulty understanding the 'clinical report', as she later explains "*I'll be sitting there with the dictionary all night*"(454-455). Wendy also reported difficulty understanding the report remarking "*these things are a bit technical*"(407-408). However, for Helen, the clinician subsequently provided a report appropriate to her level, ensuring Helen fully understood, providing her power and control. Participants appreciated the opportunity to involve their family during feedback:

*He invited my family and...went through the results again with them. (Helen:112-113)*

Although as Sheila notes it was important the decision was hers:

*It's confidential, so it was fed back to me and then I could tell, if I wanted to. (Sheila:402-403)*

Thus, Sheila was empowered to be involved in deciding how and if feedback was shared. As well as feedback, some participants appreciated being signposted to relevant support:

*I was given a lot of information about (...) [the neurodegenerative condition] and organisations, and who can help like, so they were, not just giving me feedback on how I was doing, but with other groups that can help.*  
(Sheila:257-262)

Sheila's use of 'just' suggests she experienced this as the clinician going beyond the basics of simply providing feedback. Unfortunately, one participant was unable to recall receiving any feedback at all. Of the remaining participants, Lisa reported the feedback was "*pretty prompt*"(496), but unfortunately for Arthur waiting for feedback exacerbated frustrations:

*What the tests did was excite curiosity, but then to have to wait for three weeks and then wh-, there's three months of my life left [inaudible-16:04:08], I can't understand.* (Arthur:320-324)

Thus, the frustration Arthur felt at an unexplained delay, was intensified in the context of his limited life expectancy. Furthermore, he explains, the testing "*created some impetus, some momentum*"(364-365) and that:

*It becomes less relevant, I mean the longer you leave it between two events, then the less effective it is, cos if someone says to you "by the way do you remember sixteen weeks ago we did this" and I say "no".*  
(Arthur:713-717)

Hence, for Arthur, difficulties with his memory also became a barrier to effective feedback, highlighting the significance of timely feedback.

### 3.6.2. Meaning of Results

Participants made sense of the results in a range of ways. Many participants spoke about results as 'proof' of their own sanity:

*It's helpful for my confidence to know that I haven't lost my marbles completely. (Stephen:371-373)*

*I: Can you tell me which bits you found most helpful?  
Well knowing I haven't got onset of Alzheimer's, knowing I'm not crazy.  
(Sheila:342-345)*

Thus, results provided participants reassurance of their rationality, removing the concern about dementia. As Graham vividly captures, the results confirmed he wasn't 'damaged':

*I'm not as damaged mentally as I am physically [laughter]. It's made me realise that...there don't seem to be as much damaged in the nerves in me brain, that have stopped me from being the same person mentally as I always have been. (Graham:417-420)*

Thus, for Graham, the results demonstrated he had retained his self-identity, value and personhood. In contrast, many participants spoke about results as a verification of genuine illness. For Helen, receiving "proof"(213) of her condition, allowed her to externalise difficulties:

*It's because I've got [a neurodegenerative condition] that I'm slow.  
(Helen:283-284)*

Whereas, the reverse was true for participants receiving results confirming no impairment:

*It made me realise that actually, you can't blame [the neurodegenerative condition] for everything, you know the reason that you've got odd socks on is because you've got a hangover and you're scatty. (Lisa:681-685)*

Thus, Lisa, unable to blame her condition, appears to normalise difficulties, blaming ordinary absent-mindedness. For Stephen, the results were particularly meaningful because of the objective nature of the assessment:

*You're never the best place to judge yourself are you so, people are polite you know, they're not gonna say "that's wrong", or "your mind's wondered a bit" or "what you talking about", so to get an affirmation that actually from the outside your cognitive powers are pretty good, that's quite good right.*  
(Stephen:491-499)

*I found it comforting that it was as challenging as it was.*

I: *You found that comforting?*

*Yea, yea, you know cos it could have been like you "put these square blocks in the round hole" sort of [both laugh], you know if it was patronising I'd be disappointed, annoyed. So I felt like I'd had a rigorous brain teasing test. That was important, to feel like I [inaudible- 20:39:27] had been sort of challenged. (Stephen:390-399)*

In these extracts, Stephen explains that (unlike his peers, who could not be relied upon to provide candid appraisals), the assessment bypassed 'politeness', providing an honest evaluation of his cognitive abilities. Despite the possibility of evoking feelings of 'failure', Stephen valued the challenging nature of the assessment as it demonstrated he wasn't being patronised, hence could trust the outcome.

### 3.6.3. Emotional Impact of Results

Participants found receiving results an emotional experience, and for the majority, their responses were influenced by the outcome received, especially if it was unexpected. Comparable to the experience reported during testing, participants reported difficult emotions in response to confirmed weaknesses:

*The only unhelpful thing was, finding out that things that you were bad at, and feeling a bit low initially. (Graham:458-460)*

Thus, Graham, exposed to evidence of his weaknesses, felt saddened, perhaps 'grieving' a lost ability. As Helen remarks:

*It's difficult because you have to become aware of the fact that yo-you're, you're actually dying. (Helen:495-497)*

Hesitant to name the reality, Helen highlights how results can act as a stark reminder of participant's fate. Graham reveals how this scared him:

*I've always tried to concentrate on the things that I can do, and when this test brought up the things that I couldn't do...it did sort of scare me...it made me face what-, it put down in black and white in real terms factual way, what I can't do, and I've spent the last twenty years avoiding that. (Graham:256-264)*

Thus, Graham describes receiving results as somewhat confronting, especially their formal nature which increased their permanence and factuality. It appears results forced participants to face the reality of their conditions; they could no longer use ways of coping, such as avoidance and denial, leaving participants vulnerable to emotional distress. In contrast, participants whose results showed no cognitive deficits were reassured and lifted in mood. As Lisa explains:

*It was quite handy to know that I didn't need to worry about that component of my condition. (Lisa:670-672)*

Hence, the results gave Lisa permission to put concerns to the back of her mind. Similarly, most participants reported a positive emotional impact:

*A relief, it's like a curtain lifting. (Sheila:299)*

*It was a real boost of my confidence, it was a bit of sunshine on a bit of a gloomy horizon all round. (Stephen:623-625)*



Metaphoric language was common in the interviews, with Sheila, comparing results to a 'curtain lifting', suggests she felt an insurmountable weight had been lifted and she could 'see the light' after prolonged turmoil. For Stephen, his comparison to weather indicated the results brought positivity in to an otherwise foreboding future, by reaffirming his cognitive ability and resolving his self-doubt. Perhaps the 'gloomy horizon' is symbolic of Stephen, in the 'winter' of his life, making him more grateful for sunshine (positive results). For Graham, the positive results and new coping strategies had a huge therapeutic impact:

*I've been quite depressed, but working out that thing, that was a positive thing, that was the most positive thing that's come out of the last two years really. (Graham:48-51)*

To put the enormity of this into context, when talking about both his neurodegenerative condition and depression, Graham became tearful and later explained:

*It sounds a bit extreme, but you think like, part of you has sort of died. (Graham:531-532)*

Thus, for Graham the results represented an antidote to his grief at losing part of himself, by reconnecting him to his previous self-identity. Regardless of outcome, participants reported the process as positive and helpful. Certainly, participants felt it was meaningful to share results with their families:

*I: Were the results meaningful for the family, or-  
I don't know about them, but I felt better that I had an explanation to them. (Sheila:387-390)*

*It was putting in, um, (...) er, making, um, you know your family aware of what they were gonna have to experience. (Helen:24-26)*

*For the sake of my wife and my kids, they need to, they too need to understand what's going on. (Arthur:688-690)*

For Sheila, the results empowered her with an explanation of her 'hidden' disability, whereas for Helen and Arthur, the results provided a tool to increase their family's knowledge of their conditions. The hesitant nature of Helen's extract mirrors her difficulty in broaching this topic, hence results may potentially enable a very difficult conversation for Helen and her family regarding the reality of her condition going forward. Arthur's emphasis on 'too' highlights the importance of the family's involvement, perhaps in preparation for when he will no longer understand 'what's going on'. For many, relief was shared with family members:

*[The results] gave the family some confidence, you know cos they see me struggling a bit more each week, so for me to be able to say "well cognitively I'm all there". (Stephen:554-557)*

Thus, despite evidence of decline, Stephen was able to reassure his family to a degree not possible before, as if the results corroborate his assurances.

#### 3.6.4. Coping Strategies Provided Power and Control

Participants spoke about acquiring useful strategies from the assessment, supporting them to accommodate their deficit and modify their approach to tasks:

*[The psychologist] was putting forward ideas...ways which you could compensate for those problems ...to help make your life easier. (Helen:42-49)*

*I do feel better afterwards when it's pointed out in these ways, a way that you can sort of deal or cope with it. (Graham:276-278)*

Thus, feedback seemingly facilitated future coping, or as Helen states it helps find "solutions"(16) to 'fix' her problems. As well as seeking solutions, participants spoke about coping strategies encouraging a process of adjustment and acceptance:

*I just gotta sort of accept that there are weaknesses there. (Graham:91-92)*

*It's coming to terms with it...knowing your weaknesses. (Helen:554-555)*

For others, the possibility of regaining some control over the impact of their condition proved motivating:

*At some points I've just thought "things are just gonna go downhill, there's nothing you can do about it mate", but when I saw that [feedback], I thought "well there is something you can do to help, to slow thing down". (Graham:37-41)*

Thus, for Graham, on the verge of giving up, the coping strategies provided a sense of control in contrast to previous pessimism regarding perceived inevitable decline. As Helen optimistically notes:

*There's always a way of doing things, it might not be the way you normally do it, but there's always other ways. (Helen:194-196)*

This extract suggests coping strategies empowered Helen, leaving her with a sense of positivity. Other participants also spoke about the empowering nature of feedback:

*Quite often you'll get asked in, when you go to hospital appointments, to relay your symptoms, or what not, so it was good for me to understand that I didn't have those symptoms. (Lisa:649-653)*

*If you've got knowledge of what's going on, it takes away the fear, I think, of things when they go drastically wrong. (Helen:227-229)*

Thus, participants gained knowledge from feedback, which they applied to personally meaningful situations. For Lisa, it supported her in navigating healthcare appointment, whereas for Helen it helped her manage when things

didn't go to plan. Participants who did not receive meaningful feedback on how to cope with difficulties felt sorely let down, or as Wendy describes "heartbroken"(310):

*The only thing that upset me was I was not being offered any assistance with how to deal with this, and I thought "there must be techniques that I could learn". (Wendy:517-520)*

### 3.6.5. Future Implications

For some participants, the feedback was a valuable tool, helping them prepare for future cognitive decline or consider implications for their occupational role:

*I found it useful, because I'm still working, to maybe make me think "you might want to just review when you do something at work, to make sure that you have got the ordering correct". (Lisa:23-27)*

*There's times I think, "oh yes I could do that, I could do a job" and realise I can't do a nine to five job, because I can't handle the pressure, the speed, I can do maybe those jobs, but far less of them, and at much longer time. (Helen:315-320)*

For Lisa, the feedback, despite indicating no significant impairments, introduced self-doubt over her work performance, resulting in her making adjustments. For Helen, the results highlighted difficulties she would face in a work environment, perhaps triggering a realisation of her potential lost societal value. In the following extract, it is clear feedback has made Helen consider how her role within her own family will change:

*As the years go on I do less and less work [both laugh] and they do more and more for me. (Helen:379-381)*

This is clearly significant for Helen, as she later jokes about feeling a "burden"(462). Whilst this shift in generational roles in a family's life cycle (Carter & McGoldrick, 2005) is conventional in western culture, for Helen the feedback

highlights it may be happening sooner than expected. Although feedback was experienced overwhelmingly positively, Stephen questions its future usefulness:

*You know where you stand there, until the next set of tests. (Stephen:499-500)*

Thus, Stephen acknowledges the results are only valid until the next set, highlighting the assessments inability to provide certainty over the future progression of his condition.

## **4. DISCUSSION**

### **4.1. Overview**

In this chapter the themes from analysis will be summarised and discussed in relation to the original research questions, revisiting previous literature to provide context. I will then reflect on the research process and outcomes, considering clinical implications, before discussing methodological considerations and directions for future research.

### **4.2. Brief Summary of Analysis**

The analysis generated four superordinate themes: expectations of assessment, relationship with clinician, experience during testing and outcome of assessment. Overall, the experience of neuropsychological assessment was emotion evoking, with participants endeavouring to cope with, and make sense of the experience throughout. Whilst individual experiences varied, and although participants reported negative aspects of testing, most talked about the process as a positive experience. In deciding to undergo assessment, participants appeared to weigh up their own and other's desire for understanding, against the potential for negative outcomes. In terms of the rationale for assessment, participants hoped it would provide objective evidence of suspected or 'hidden' cognitive deficits, and provide a measure of their condition's progression, an increased understanding and help to cope with potential impairments. Participants had mixed views as to whether assessment was mainly for their own benefit or a powerful tool utilised by clinicians to gather information.

Participants said that the relationship with the assessing clinician was vital in determining their experience and helping them to withstand the emotional stresses of testing. Participants appreciated the emotional warmth and collaborative nature of the clinician, and valued feeling genuinely listened to and heard, whilst also respecting the clinician's expertise and power to influence. Familiarity with the clinician was talked about as preferable as it generated

feelings of trust and improved mutual understanding. Feelings of uncertainty were voiced regarding unfamiliar clinicians, although these could be lessened if the participant felt they had been otherwise well-prepared for the process.

Participants spoke about diverse experiences during the testing; on one hand enjoying the challenge and sense of retained ability, whilst at other times questioning their ability and sensing poor performance, the latter resulting in feelings of frustration, stress, fear and disappointment. To cope, participants used an array of strategies: focusing on the positive, normalising anxiety, minimising 'failure', and denying the test's difficulty, in order to complete the test whilst maintaining a positive sense of self. Participants viewed the testing as prolonged, intense, fast-paced and hard work, with some drawing comparisons to being back at school. The assessment environment was highlighted as important, with distractors felt to negatively impact performance.

There was an overall sense the assessment provided objective 'proof' of the presence or absence of cognitive deficits. Participants expressed the view that the feedback empowered them, providing an explanation and understanding of any deficits, and resulting in coping strategies to adjust and retain control over areas of difficulty. Participants valued written and accessible feedback, and the option to involve family members in the feedback process, to help increase relative's awareness of their condition. Negative experiences predominantly related to the absence of suggested coping strategies and feedback that was delayed or communicated in a way that was experienced as technical. Participants described mixed responses to feedback; positive feedback had a therapeutic impact, reconfirming participant's self-identity and providing a sense of relief and confidence, whereas feedback confirming deficits had the potential to be confronting, with participants forced to face the objective description of their condition.

In conclusion, the analysis suggests that the process of neuropsychological assessment was experienced as intense and fraught with potential emotional challenges, including the possibility of being exposed to evidence of lost functioning. Yet, despite this, most emerged with a sense of having benefitted

from the experience, grateful for confirmation of retained abilities or strategies to cope with impairments. The issues raised by the analysis have significant implications for clinical and ethical practice.

### **4.3. Consideration of Findings in Relation to Research Questions**

#### 4.3.1. What Do People with A Neurodegenerative Condition Say About Their Experience of Neuropsychological Assessment, and How Do They Describe This?

In this section, the first two research questions will be considered together. Elements of participant's experience that were considered helpful or unhelpful will be discussed in section 4.3.4.

*4.3.1.1. Deciding to undergo the assessment:* Participants described an internal struggle to balance the desire to undergo assessment, with the fear of potential unwanted outcomes. Despite apprehension, participants sensed assessment was the 'right' thing to do and would help them and others, hence they possibly felt obligated to continue. Unfortunately, literature exploring client's decision whether to undergo assessment is non-existent. Participants implied an external encouragement to undergo assessment, perhaps from family members or professionals. This is similar to findings by Blake (2004) and Owen (2012) suggesting neuropsychological assessment was comparable to other medical procedures participants were 'told' to undergo, with participants generally happy to oblige a trusted professional, almost unquestionably, even when they were without a clear rationale as to why. Blake (2004) noted 'coerced' assessments usually resulted in more threatening and less satisfactory experiences, highlighting it is preferable for clients to have an independent desire to undergo assessment.

*4.3.1.2. Subjective awareness of performance:* Participants reported a subjective awareness of their own performance during testing, at times sensing success, whilst at other times perceiving 'failure' when participants sensed they performed poorly, faced with tasks they found difficult or impossible. This is consistent with findings of Keady & Gilliard (2002) who described participants as adopting a self-



evaluative stance towards their own performance, and Krohne et al., (2011) who described participants who felt the burden of developing their own interpretations.

*4.3.1.3. Coping with testing:* Participants described using self-protective coping strategies to alleviate distress and maintain a positive sense of self throughout testing, ranging from remaining task-focused and focussing on the positive, to normalising 'failure', discontinuing tasks and recalling previous experiences to help put testing in perspective. Similar use of strategies has been reported in previous studies, including Owen's (2012) study where participants described switching off and remaining positive, Conniff's (2008) study where children reported using distraction, humour, concentration to focus on tasks, and Keady & Gilliard's (2002) study where older adults with suspected dementia relied on others for clarification and used 'strategic resistance' and 'making excuses' to buy themselves more time to figure out what was happening.

*4.3.1.4. Importance of environment:* Participants expressed the importance of the assessment environment, describing how distractors were problematic for their ability to concentrate, hence impacting their performance. Other than the significant negative impact of distractors, for which participants often blamed themselves, participants otherwise reported satisfaction with the assessment environment, similar to findings by Bennett-Levy et al. (1994), but dissimilar to studies where participants commented on problems with room size and temperature (Keady & Gilliard, 2002; Owen, 2012; Westervelt et al., 2007), lack of waiting rooms (Foran et al., 2016) or the room being unfriendly and medicalised with "pictures of brains...on the walls" perpetuating anxiety (Keady & Gilliard, 2002, p.17).

*4.3.1.5. Meaning of results:* Overall participants reported gaining feedback that was meaningful. Some participants talked about the results as proof of retained ability and sanity, while some felt results provided proof of their condition and objective evidence of suspected cognitive decline. Participants receiving confirmation of cognitive ability spoke of feeling reassured, retaining their self-identity and value, as if the possibility of cognitive decline had undermined their personhood, as Kitwood (1997) described in people with dementia. Participants

receiving confirmation of impairments, spoke of feeling the impact of their condition had been validated and legitimised, especially as cognitive decline had otherwise felt 'hidden' compared to physical aspects. Vast amounts of the literature support this, with participants reporting the importance of validation (Bennett-Levy et al., 1994; Blake, 2004), even if the results were merely a confirmation (Westervelt et al., 2007), and participants with TBI reporting the results were proof they were 'not making it up' (Nochi, 1998), resulting in relief of understanding difficulties (Owen, 2012).

*4.3.1.6. Future implications:* Participants talked about the assessment causing them to question and adjust occupational and family roles, highlighting potential accelerations to participant's family life cycle (Carter & McGoldrick, 2005), although as Rosado et al. (2017) noted feedback improved participant's ability to cope with transitioning out of work roles and turn responsibility over to other individuals. In Conniff's (2008) study, implications were also described by children who noted the social implications of having to move groups at school following the assessment. Participants also questioned the future usefulness of the assessment in the face of an ever-changing and progressive condition.

#### 4.3.2. How Did the Experience Make Them Feel?

*4.3.2.1. Emotional response to testing:* Participants described a range of emotional responses to testing, which in the absence of feedback, tended to be based on participants own appraisal of their performance. Enjoyment following perceived success, was replaced with feelings of frustration, disappointment and self-doubt, when participants sensed they performed poorly, leading them to subsequently question their ability. Participants experienced perceived 'failure' as highlighting possible cognitive decline, threatening participant's sense of self, especially on tests they felt were 'basic' or would previously have been within their sphere of competence. The range of emotions reported including pleasure, frustration, anxiety, nervousness, confusion; which are similar to those captured by other studies, (Bennett-Levy et al., 1994; Conniff, 2008; Keady & Gilliard, 2002; Owen, 2012).

Whilst perceived performance had an immense impact on how participants felt, emotional responses were also influenced by participants own histories. For instance, participants who mentioned histories of depression, perfectionism or being overly critical, reported being susceptible to feeling low and disappointed. Feelings of self-doubt seemed particularly widespread, as participants, in response to their diagnosis of a neurodegenerative condition, talked about constantly doubting the presence of their own abilities. Overall, although testing evoked mostly negative emotional responses, participants said that the testing needed to be challenging to provide beneficial outcomes (e.g. objective evidence). Although prepared for the practical elements of assessment, participants did not appear to feel prepared for the emotional reality of assessment.

*4.3.2.2. Emotional impact of results:* To some degree, this mirrored the emotional response participants reported during testing, in that a confirmation of cognitive deficits resulted in difficult emotions, as participants were confronted with evidence of cognitive weakness, and the subsequent impact on self-identity (Krohne et al., 2011). This is similar to previous studies that noted repeated 'failure' can strengthen feelings of incompetency (Cheston & Bender, 2005) and depression (Bennett-Levy et al., 1994) and negatively reinforce the impact of the condition (Owen, 2012). However, for participants receiving reassurance of retained ability, there was a therapeutic shift towards feeling emotionally optimistic. Participants described feeling a huge sense of relief (shared with their family), their confidence and self-identity positively boosted, consistent with previous findings where participants responses were influenced by outcome of the assessment (Robinson, 2016). In the current study the emotional impact was not only influenced by the outcome of the assessment, but also how participants made sense of the results and the style of the feedback. For instance, some participants, despite scoring poorly, reported a positive emotional impact as the assessment verified their condition and provided ways to cope with deficits. While for many, the testing itself was filled with emotional turmoil, most participants felt that through the process they had achieved a meaningful and worthwhile outcome.

#### 4.3.3. What Was Their Understanding of Why They Were Assessed?

*4.3.3.1. To measure cognitive decline:* Participants reported that the assessment was to discover potential cognitive deficits, to find out how much their cognitive abilities had been impacted, and to measure progression of their condition. Some participants presented a more limited understanding of the assessment as a tool utilised by professionals to discover problems in order to determine ways to help. Overall, participants talked about having a satisfactory understanding, reflecting what they had previously been told by their clinician or based on their own personal understandings if the rationale was not made clear (Keady & Gilliard, 2002). With a reported relationship between degree of preparation and overall experience of the assessment (Bennett-Levy et al., 1994), the level of preparation experienced by participants in this study may link to participants reported satisfaction with the experience. Previous studies found patients were poorly prepared, such as Blake's (2004) doctoral thesis where one participant reported "nobody told me anything about it", or as in the study by Bennett-Levy et al., (1994) where only half of participants felt adequately prepared for the assessment. Hence the shift in 'preparedness' may have resulted from implementation of policy recommendations to improve pre-assessment preparation (Foran et al., 2016; Owen, 2012). That said, participants did not report on whether they were told more specifically what to expect from being tested.

*4.3.3.2. Anticipating understanding and coping advice:* Participants approached the assessment with a desire for explanations and coping strategies to help them understand and manage impairments. This was an unmistakable and shared request to emerge from interviews, highlighting participant's strong need to find meaningful solutions to everyday problems and maintain a sense of control over their cognitive ability. Hence, this study suggests people with neurodegenerative conditions hold the same desire for information as patients experiencing other chronic health conditions (Meredith et al., 1996; Nease & Brook, 1995). This contrasts with hypotheses suggesting clients may choose to limit their understanding to emotionally protect themselves (Owen, 2012). The desire for strategies is highly similar to findings by Blake (2004), but appeared in contrast to the study by Bennett-Levy et al. (1994) which found only 50% were aware the

assessment could help them 'get around' problem areas in their life. This difference could reflect that whilst clients have always desired information, a lack of preparation for assessment left them unaware of the possibility of gaining practical strategies until recently. As awareness increases, perhaps clients are feeling empowered to request this as an outcome (Ocloo & Matthews, 2016).

#### 4.3.4. What Do They Find Helpful or Unhelpful About the Process?

The main findings covering helpful aspects seemed to relate to participant's relationship with the clinician. The assessment feeling intense and prolonged was considered an unhelpful aspect of the assessment. The findings relating to 'communication of results' and 'coping strategies providing power and control' highlighted both helpful and unhelpful aspects of the process.

*4.3.4.1. Positive clinician qualities supported coping:* Participants indicated the clinician-patient relationship as key in facilitating the assessment process and ability to cope with the emotional demands of testing, with good therapeutic rapport reported as potentially improving uptake of recommendations. This is consistent with various studies reporting participants valued the clinician's respect and listening skills (Owen, 2012), organisational skills (Foran et al., 2016), awareness of the person's context and the person as an individual (Blake, 2004; Lee, 2012), and taking time to explain the process and feedback (Foran et al., 2016; Owen, 2012; Westervelt et al., 2007). Certainly, in both current and previous studies, lack of therapeutic rapport was a lead contributing factor for participants reporting negative experiences (Blake, 2004; Owen, 2012). The findings support the claim that therapeutic alliance is an essential foundation, and significantly impacts on therapeutic and healthcare outcomes (Kelley, Kraft-Todd, Schapira, Kossowsky & Riess, 2014; Martin, Garske & David, 2000) and enhances engagement and outcome of testing (Prigatano, 2000). However, there is some disparity with Robinson's (2016) study, where participants experienced the clinician as occupying two opposing roles: as person-centred during clinical interview but didactic and task-focused during testing. Furthermore Bennett-Levy et al., (1994) suggest it may be 'the system', including the service, which has a more powerful impact on participant's experience rather than the individual clinicians.

*4.3.4.2. Familiarity and trust:* Participants described preferring familiar clinicians, with whom they had good therapeutic rapport, and therefore trusted to provide objective answers. They said that familiar clinicians created a safe space, allowing openness and vulnerability, improving mutual understanding. For participants known to clinicians, the assessor was aware of participant's histories, allowing them to recognise individual qualities, provide individual reassurances and potentially increase adherence to recommendations. Previous studies similarly advocate for a good relationship with the assessing clinician prior to assessment (Keady & Gilliard, 2002; Owen: 2012) which has been suggested to improve overall satisfaction with the process (Foran et al., 2016). Feelings of uncertainty and anxiety were voiced regarding the idea of an unfamiliar clinician, as in previous studies where the lack of familiarity of new professionals increased anxiety prior to assessment (Conniff, 2008; Owen, 2012). An unfamiliar clinician did not necessarily result in a negative experience, especially if the participants had been well-prepared by a familiar clinician, although as Owen (2012) notes unfamiliar clinicians had to work hard to establish a relaxed atmosphere and build rapport to reduce anticipatory anxiety.

*4.3.4.3. Expertise and power:* Participants described appreciating clinician's expertise, regardless of their level of training. This is consistent with several studies which highlight that establishing rapport is more essential than the clinician's qualification level (Bennett-Levy et al., 1994; Blake, 2004; Donofrio et al., 1999; Westervelt et al., 2007). The only exception is noted by Owen (2012) where a participant reported strong negative feelings regarding the perceived lack of qualifications by the assessor. Participants described appreciating the power held by clinicians, especially when it was used to help achieve a desired outcome. Whilst appreciating clinician's power, participants also appreciated instances when power was lessened, such as clinicians providing understandable feedback. Previous studies suggest participants accepted a relatively powerless, passive role during assessment (Conniff, 2008; Owen, 2012).

*4.3.4.4. Communication of results:* Participants talked about valuing feedback that was comprehensible, written and pitched at an appropriate level, in line with

the BPS's (2002) Code of Good Practice for Psychological Testing which states feedback should be clear and appropriate to client's level of understanding. Participants commented that sharing feedback with their family was a way to communicate difficulties, similar to findings by Blake (2004) who suggested it also reinforced advice regarding coping strategies. Negative experiences predominantly related to delayed or inaccessible feedback, reducing the potential to facilitate learning, with similar findings previously reported, including difficulty understanding or remembering feedback (Bennett-Levy et al., 1994; Foran et al., 2016), client's feeling disempowered by unexplained terms (Owen, 2012), and distress exacerbated by waiting for feedback (Robinson, 2016). In contrast, Blake (2004) found participants did not report concern over delayed feedback if they had been informed of likely timescales. One participant reported the clinician appeared hesitant to deliver negative feedback, which bore similarities to findings by Blake (2004) who hypothesised clinicians may be avoiding challenging therapeutic responsibilities, especially in contexts where they feel overstretched, despite studies suggesting it is not in the best interest of the client.

*4.3.4.5. Coping strategies provided power and control:* Participants reported feeling empowered by feedback that facilitated coping and enabled them to retain a sense of self as capable and in control, mirroring experiences of those with suspected dementia (Robinson, 2016). This builds upon previous studies where participants reported feedback and recommendations as helpful (Donofrio et al., 1999; Westervelt et al., 2007), especially understanding the application of results to everyday life, including practical advice on coping strategies to help get around problem areas (Bennett-Levy et al., 1994; Blake, 2004), to improve daily functioning (Owen, 2012) and increase quality of life (Rosado et al., 2017). As Bennett-Levy et al. (1994) stated, the *usefulness* of feedback was key in determining participant's experience of assessment. Participants spoke of strategies triggering a process of adjustment and acceptance, similar to previous studies, with new knowledge providing power (Foucault & Gordon, 1980) and aiding self-acceptance (Conniff, 2008; Owen, 2012). As Blake (2004) explains, the assessment, with a "high degree of threat...to the person's sense of cognitive integrity, can provide opportunities for significant learning" (p.101). Participants who reported a lack of suggested strategies, described feeling unsupported,

highlighting the importance of providing meaningful feedback including potential strategies.

*4.3.4.6. Intense and prolonged:* Participants described the testing as intense, lengthy, repetitive, fast-paced and hard work, comparable to descriptions in other studies of the testing as relentless, time-consuming, difficult and exhausting (Bennett-Levy et al., 1994; Conniff, 2008; Foran et al., 2016; Westervelt et al., 2007). Participants spoke about feeling pressurised due to timed aspects, resulting in feelings of anxiety, panic and frustration, which were potentially exacerbated when coupled with common symptoms of neurodegenerative conditions (e.g. slowness or fatigue). This is consistent with studies where participants felt rushed (Foran et al., 2016) and discomfort at being timed (Bennett-Levy et al., 1994). Alike Owen's (2012) study, some participants referenced the similarity of testing to formal examinations at school, perhaps highlighting participants felt unpractised and not in control. In addition, participants described testing as a lengthy process, but did not explicitly state it was tiring or too long as in previous studies (Bennett-Levy et al., 1994; Conniff, 2008; Owen, 2012). This perhaps reflected the flexible approach adopted by the service recruited from, where testing was often split across numerous sessions, hence participants were more likely to experience the testing as lengthy rather than tiring. Participants in the current study expressed their appreciation for splitting testing sessions and studies suggest it may improve patient satisfaction (Bennett-Levy et al., 1994).

#### **4.4. Consideration of Findings in Relation to Previous Literature**

The findings confirmed that the experience of neuropsychological assessment as viewed by people with neurodegenerative conditions, was largely consistent with previous literature that looked at various clinical populations. For instance, previous studies similarly concluded assessment was mostly experienced as positive (Bennett-Levy et al., 1994; Donofrio et al., 1999; Longley, Tate & Brown, 2012; Mountjoy et al., 2017; Westervelt et al., 2007), despite the testing being experienced as tiring, frustrating and long (Bennett-Levy et al., 1994; Conniff, 2008; Owen, 2012; Westervelt et al., 2007). Likewise, numerous studies also



highlighted the importance of the relationship with the clinician (Blake, 2004; Foran et al., 2016; Owen, 2012), the test environment (Bennett-Levy et al., 1994; Foran et al., 2016; Keady & Gilliard, 2002; Owen, 2012; Westervelt et al., 2007), and the value of written feedback and coping strategies (Bennett-Levy et al., 1994; Blake, 2004; Donofrio et al., 1999) to improve quality of life and support acceptance (Rosado et al., 2017).

Although this study has not set out to draw comparisons between groups, it is worth highlighting a few notable differences from the previous literature, which may therefore, be specific to people with neurodegenerative conditions. For instance, participants spoke about weighing up a desperate desire to measure potential progression of their condition, whilst simultaneously fearing a negative outcome. Additionally, whilst Keady and Gilliard (2002) noted participants took a self-evaluative stance; unlike previous studies, participants in the current study described an acute awareness of their perceived performance throughout testing, in particular a strong sense of self-doubt. This appeared linked to the fact that the test may provide proof of their 'sanity' or progression of their illness, and appeared to exacerbate the experienced intensity. Yet strikingly, it appeared that regardless of outcome, number of assessment or stage of disease, participants reported benefiting if they gained either a sense of reassurance in relation to retained abilities, or strategies for coping with, accepting and communicating difficulties to others.

## **4.5. Clinical Implications and Recommendations**

### **4.5.1. Introduction and Preparation for Neuropsychological Assessment**

The importance of pre-assessment preparation, including wanting to be provided with detailed and ongoing explanation about the nature and process of assessment, was highlighted by this study, with participants reporting various views regarding their expectations of assessment. Ideally, a pre-assessment meeting would allow exploration of the client's beliefs, relationship to help and understanding of the referral, utilising systemic questioning, such as 'whose idea was it for you to come and see us?', 'what do you think that person was hoping for?', and 'what were you hoping for?' (Reder & Fredman, 1996). As well as

exploring their views of the problem and concerns about the process, this style of questioning can reduce power imbalances, encouraging a collaborative approach, promoting engagement and building therapeutic rapport. In addition, prior to meeting, it may be beneficial to contact the referrer to map the network (as numerous professionals can often be involved), considering 'who is asking for what from whom?', and ascertaining who may be a useful resource in terms of supporting the client to implement recommendations.

If time constraints in the NHS context prevent a pre-assessment meeting, patients should be sent preparatory information in advance of the assessment, which could be in the form of a letter, leaflet or link to an online video. This should outline the purpose of the assessment, what it entails, the approximate length, the location and clinician that will conduct the assessment, common reactions, and finally details regarding how and when feedback will be received, how the results will be used and who they will be communicated to. It may also be beneficial to educate referrers to provide better information to potential clients, as this can provide more realistic expectations of what can be achieved through assessment, reducing disappointment, and significantly impacting attendance rates and overall satisfaction (Bennett-Levy et al., 1994; Webster; 1992).

One additional consideration, is that participants described a range of emotional reactions in response to assessment, suggesting clinicians should not only fully explain the process, but should prepare clients for the emotional experience. Especially important, as many participants reported not undergoing formal examination since childhood, and with the consequence of 'failing' confirming cognitive difficulties, increasing the sense of threat. To normalise emotional reactions, clinicians should discuss the potential for the assessment to be experienced as emotionally intense, allowing the person and clinician to identify helpful ways to manage this, hopefully enabling a sense of control, and encouraging clients to seek support if necessary. It may be helpful to point out most clients receive an outcome they feel is beneficial, however it may be worthwhile considering how the person may feel if they do not receive their desired outcome, facilitating truly informed consent.

Given that neuropsychological assessment is a lengthy, resource heavy and emotionally intensive experience, it is paramount clinicians ensure people are not unnecessarily assessed, and that clients themselves express an independent desire for testing. It may be helpful for clinicians to regularly review the decision-making process to offer neuropsychological assessment and the outcomes of those assessments, to consider whether current practice best meets client's needs, or whether there are other ways to reach satisfactory outcomes without the person needing to undergo a full neuropsychological assessment, which may benefit clients and promote effective use of clinical resources. However, of note from an ethical standpoint is that all participants, regardless of the outcome or stage of disease, reported benefit from either confirmation of their abilities or strategies to help them cope with and accept impairment. Therefore, it would only be ethical not to offer assessment if it was probable that neither of these outcomes would be achieved.

#### 4.5.2. Relationship with Clinician

The therapeutic relationship between the client and clinician, emerged as an important factor in the assessment experience, with participants valuing a collaborative approach, in which they felt respected, listened to, and put at ease with an empathetic, open and honest approach. Furthermore, it appears clients prefer being assessed by a familiar clinician, who they have met at least once before. Where this is not possible, clinicians should always aim to build rapport prior to testing, to reduce anxiety and increase comfort. In addition, whilst participants appreciated the expertise of the clinician, which is at times required, to reduce potential power imbalances it may be beneficial to adopt the position of 'expert non-expert' (Harper & Spellman, 1994), especially during the pre-assessment and feedback phases, where the clinician can complement clients on their skills, whilst acknowledging the need for assessment and coping strategies.

As highlighted in the study, not receiving feedback during testing increased participant's uncertainty about their performance, emphasising the need to balance maintaining a warm and empathetic approach whilst maintaining standard administration. In light of this, it could be recommended that test manuals incorporate standardised strengths-focused responses during testing

administration (e.g. 'you are working hard'), that externalise the problem (White, 2007) and provide reassurance (e.g. 'the tests are designed so everyone fails at some point'), particularly for anxious clients for whom the experience of 'failure' is likely to have a significant impact on self-confidence (Bennett-Levy et al., 1994). As Shapiro (1951) notes, clinicians who randomly distribute praise (not just following correct responses) are no more revealing answers than if they remained silent throughout, and this can only serve to improve the experience for clients.

This highlights that although tests themselves are standardised, the way they are applied can greatly alter the experience, and requires great skill on behalf of the clinician. With that in mind, the findings have implications for clinical psychology training, as inexperienced clinicians tend to focus on the 'technical' aspects of neuropsychological assessment (e.g. the selection, administration and interpretation of tests), as does the literature (Lezak et al., 2012). It may be beneficial for newer clinicians to be aware of the qualitative aspects of the process to maximise therapeutic opportunities, and for training institutions to consider how best to support trainees in this endeavour, not presenting the discipline of neuropsychology as separate from the core skills of clinical psychology.

#### 4.5.3. Conducting Neuropsychological Assessment

Optimal assessment conditions should be prioritised, following reports of inadequate assessment environments, especially environmental distractions impacting the experience of testing and participants ability to 'perform'. Despite possible limits to resources, clinicians should ensure the environment is as appropriate as possible; with limited distractions, adequate space, comfortable furnishings and suitable lighting and temperature. This can be increasingly challenging for assessments conducted in patient's homes, hence it can be beneficial for clinicians to be familiar with the home set up prior to testing, and to pre-empt and minimise potential distractors (e.g. silencing mobile phones, facing client away from windows, and planning the absence of other household occupants). As supported by Bennett-Levy's et al. (1994) findings, testing sessions should be flexible, with opportunities for split sessions and rest breaks.

#### 4.5.4. Feedback and Coping Strategies

In view of the study highlighting difficulties with delayed and inaccessible feedback, and a lack of coping strategies, it is clear clinicians could improve provision of comprehensible and meaningful feedback, especially as it has the potential to improve patient's quality of life and ability to cope (Rosado et al., 2017). No official guidance exists for feedback of neuropsychological assessment, however as mentioned earlier, Gass and Brown (1992) recommend provision of feedback in a six-stepped approach, focussing on relative strengths and weaknesses, the meaning of results for daily life, and recommendations of coping strategies to adapt to problem areas, which should match the nature and stage of the condition (Moos & Schafer, 1984). The focus on areas of strength, as well as coping strategies, may be particularly therapeutic for patients diagnosed with neurodegenerative conditions, who may underestimate their cognitive ability, and therefore will likely derive emotional benefit from the objective confirmation of ability (Gass & Brown, 1992).

As emphasised in the current study, feedback regarding performance should be considered essential and provided directly by the clinician, in-person, in an understandable (providing psycho-education if necessary), collaborative, sensitive but direct and timely manner, allowing sufficient time for clients to digest, discuss implications and develop mutually agreed coping strategies and treatment plans (Foran et al., 2016; Westervelt et al., 2007). Feedback could be provided across multiple sessions if necessary, which may enhance adherence to recommendations and reduce risk of misunderstandings (Brenner, 2003; Lopez, Roberts, Tchanturia & Treasure, 2008). This should be swiftly followed by a written summary of the assessment findings and recommendations, particularly beneficial for cognitively-impaired populations who may be empowered by short simple summaries of complex information to aid recollection (Fallows & Hilsabeck, 2013; Gass & Brown, 1992; Smith et al., 2007). The client must be involved in deciding who receives assessment results, with the opportunity to invite members of their system to the feedback session if desired. This can be beneficial, particularly if the client is anxious about the results, which can interfere with them absorbing and recalling information relayed by the professional (Ley,

1988), hence family members can act as 'collaborators' in the feedback process, increasing client's ongoing understanding (Postal & Armstrong, 2013).

## **4.6. Methodological Considerations**

This section provides a critique of methodological issues within the current study, evaluating it in line with recommended procedures for the critical appraisal of qualitative research and highlighting its limitations.

### **4.6.1. Demonstrating Validity and Quality in Qualitative Research**

The typical standards used to assess quantitative approaches risk being overly simplistic or prescriptive for effectively assessing qualitative research (Smith et al., 2009). Instead, the quality of qualitative research is judged by its thoroughness, trustworthiness and meaningfulness, and Yardley (2000) proposes numerous broad ranging criteria that can be applied regardless of theoretical orientation. I have strived to meet these principles throughout the research process and will now briefly outline and demonstrate each in relation to the current study.

*4.6.1.1. Sensitivity to context:* This can occur in various ways throughout the research process, and includes sensitivity to participant's perspectives, the data collected, and the sociocultural context of the research (Yardley, 2017). The current study demonstrated sensitivity to context, firstly by presenting an awareness of existing literature, both on the topic and method used. Secondly, great care and skill was taken designing and implementing the study, for instance conducting interviews in an empathetic manner, whilst negotiating and adjusting the interview style for possible cognitive difficulties and attempting to reduce power differentials to encourage participant's free expression. Thirdly, sensitivity to data was achieved during the immersive analytic process and displayed in both the audit trail (see Appendix K) and throughout the narrative account by grounding possible interpretations using a substantial number of extracts from participants, ensuring claims were not pre-conceived, but cautious and appropriate to the sample (Smith et al., 2009). Finally, the reflective journal and subsequent personal reflections presented in this chapter, allowed me to consider

how the wider context influenced my own beliefs and assumptions and that of participants.

*4.6.1.2. Commitment and rigour:* Yardley (2017) states that commitment and rigour can be demonstrated through “in-depth engagement with the topic, including thorough data collection, displaying expertise and skills in the methods employed, and undertaking a detailed, in-depth analysis” (p.295-296). To ensure commitment in the current study, I was dedicated to developing competence in core research skills, reading the IPA literature extensively and attending workshops on the subject. I was aware that researcher’s analysis often becomes deeper and richer as they gain experience (Smith, 2011), so as novice qualitative researcher, I was determined to counteract this as much as possible. Practicing the interview technique allowed me to actively listen and pay close attention to participants accounts during data collection, and personally transcribing and re-reading all interviews allowed me to become immersed in the data. Throughout the entire process, from planning to analysis of results, I met regularly with my research supervisor to seek guidance on the process.

To ensure rigour, the sample was carefully selected to be relatively homogenous (as favoured in IPA; Smith et al., 2009) and the interview schedule was used flexibly, allowing me to follow up on important cues, resulting in the emergence of rich data. The analysis adhered to the framework suggested by Smith et al., (2009), conducting extended exploration of the data, and endeavoured to be sufficiently interpretative, grounding interpretations in substantial quotes that evenly represented each participant. The research supervisor, experienced in supervising IPA, independently reviewed sections of my analysis, resulting in broadly similar themes, and highlighting possible modifications to refine and add richness to my analysis, whilst respecting the double hermeneutic process. This was an attempt to mutually confirm consistency of themes (Knafl & Breitmayer, 1991) and employ contextualist triangulation, which aims to enhance completeness, but not necessarily objectiveness (Madill, Jordan & Shirley, 2000). Furthermore, respondent validation was considered to further determine the credibility or ‘fit’ of themes, but was decided against on several bases, including that it would place unremunerated demands on participants (both emotionally and

time-wise) and would raise ethical dilemmas in considering how much to alter analysis based on individual concerns (Barbour, 2001; Mays & Pope, 2000).

*4.6.1.3. Transparency and coherence:* “Transparency means the reader should be able to see clearly how the interpretation was derived from the data” (Yardley, 2017, p.296). Hence in the current study, the data collection and analytic process have been described in detail, themes clearly evidenced with quotes, and an audit trail and a worked example of a transcript included (see Appendix J and K). Coherence refers to the clarity of the constructed argument and examines the appropriateness of the underlying epistemology, method and analysis to respond to the research question (Yardley, 2000). To ensure coherence in the current study, numerous drafts were completed and the methodological approach chosen was considered the best fit with the epistemological position of critical realism and the study’s aims of exploring individual’s experience.

*4.6.1.4. Impact and importance:* Yardley (2000) argues the ultimate value of research is whether it generates knowledge considered important or useful, that has a theoretically, clinically or socio-culturally impact on how we view the world. The current study aimed to increase understanding of the experience of neuropsychological assessment, specifically from the viewpoint of people with neurodegenerative conditions, allowing participants to feel valued and hopefully resulting in recommendations to guide clinicians, further refining and improving clinical practice. It is hoped the focus and novel design of the study will add enormous value to the paucity of literature in this area.

#### 4.6.2. Limitations

*4.6.2.1. Recruitment:* Recruiting participants proved problematic, and I reflected this may be one reason this group’s voices are not heard. This led to an early revision of inclusion criteria resulting in removal of the upper age limit. Furthermore, as potential participants were identified by clinicians, there is a possibility of bias in participant selection. For instance, as the study focuses on participant’s experience, some clinicians may have felt concerned their therapeutic skills were being evaluated, causing them to be reluctant to suggest potential participants, or selecting those they perceived as having a positive



experience. Additionally, for neuropsychological assessments that took place whilst the study was actively recruiting, clinicians would have been aware the person may take part in the study, hence they may have acted differently (e.g. providing clearer explanations, showing increased empathy). Lastly, as participation was voluntary, those who agreed to take part likely did so out of interest for the topic or because they had something they wanted to share (positive or negative), potentially skewing the sample as the study was unable to capture views of those who declined to take part.

*4.6.2.2. Homogeneity of sample:* As noted earlier, IPA recommends a relatively homogenous sample in the sense that participants have experienced a similar life event, in this case a neuropsychological assessment to assess potential cognitive deterioration caused by a neurodegenerative condition. It could be argued the current sample lacked homogeneity in terms of demographic and clinical characteristics (e.g. age, gender, diagnosis, length of diagnosis, the clinician, the time since and outcome of the assessment), and these differences may have coloured the experiences reported in participants accounts. For instance, studies suggest people report increased satisfaction with healthcare if they are older (Hordacre, Taylor, Pirone & Adams, 2005) and if their experience was more recent (Mountjoy et al., 2017).

Furthermore, differences between various neurodegenerative conditions, including specific disadvantages and varying trajectories, such as the tremor specific to PD, the unpredictable course of MS, the hereditary properties of HD or the rapid and fatal progression of MND and MSA, may have influenced how the assessment was perceived and whether it felt more or less helpful. Likewise, with age and sex differences across diagnoses, for instance PD affecting more males and MS more likely to affect younger females, there is added variation between the different conditions contained within the sample. However, to remove all differences between participants is neither pragmatic or necessary, hence it was felt the similarity in life events that participants shared was sufficient for analysis of the phenomenon.

**4.6.2.3. Generalisability:** It is recognised that as an idiographic approach, IPA is limited in terms of generalisability of findings (Smith et al., 2009), instead emphasising in-depth accounts of a few individuals, with the aim of contributing to a gradually developing knowledge base (Smith & Osborn, 2007). An example of the limited generalisability in the current study, was that participants were white European, hence their accounts may not reflect experiences of people from other ethnicities and cultures, who may report different experiences, especially as neuropsychological tests, at least in part, represent culturally learned ability (Ardila, 1995) and may not be performed in the person's native language. Similarly, all participants were recruited from a single service, hence their described experience may be influenced by other therapies received at the service or processes specific to that department. Therefore, participant's account may not reflect experiences across other neuropsychology services, although it is worth cautiously noting that practices are likely to be similar to those used in other neuropsychology services across the UK. Whilst both examples ensure, to some degree, that accounts are obtained from participants with a shared experience (in keeping with IPA principles; Smith & Osborn, 2003), it is important to balance this with the need to expand and replicate the current study in other populations, to broaden claims that can be made from the findings.

With the concept of generalisability stemming from a positivist epistemology, it may be more beneficial to instead consider *transferability*, which places responsibility on the reader to cautiously make connections between their own experience and the study (Trochim, 2006). In this sense, it is possible for study findings to "give rise to explanations which potentially apply to new cases" (Willig, 2001, p.82). In considering the literature, there are limited studies with which to compare, yet findings from this study appeared consistent with previous findings in other populations, and I am confident my interpretations have captured experience that is likely to be shared by other people with a neurodegenerative condition who undergo a neuropsychological assessment.

**4.6.2.4. Interviews:** Qualitative interviews have been critiqued for being potentially artificial and misleading (Potter & Hepburn, 2005), for instance social desirability bias may cause participants to respond to questions in a certain way to be

viewed favourably. Despite being fully briefed on anonymity, participants may have felt reluctant to express dissatisfaction, assuming I was directly employed by the service, hence I ensured to explicitly highlight my relationship with the service. On reflection, I considered how prompts during the interviews acted to reinforce participant's answers, steering conversation and ultimately impacting the themes generated. To avoid overly pursuing certain responses or topic areas, I was mindful of my body language, prompts and potentially leading questions, always finishing interviews offering participants to opportunity to tell me anything not covered in the interview.

#### **4.7. Personal Reflections**

As a researcher new to qualitative interviews, I was apprehensive about transitioning from the role of therapist to researcher, and mindful to clearly introduce my role at the beginning of interviews, ensuring I tailored questions towards the research focus. Occasionally, I would notice a tendency to 'slip back' into a therapeutic role, especially if participants asked me a direct question regarding their assessment, although I was able to notice this more rapidly as I became more experienced, instead advising participants to contact a professional at the service. Concerned about not achieving a 'rich' interview, I reminded myself prior to meeting participants to maintain a slow pace, ask questions infrequently and allow participants time to fully answer questions (Smith et al., 2009). However, due to a mixture of participant's cognitive difficulties and my reluctance to interrupt, the first interview was considerably longer than expected, yet failing to interrupt meant the participant fatigued as we began to revisit earlier topics at a deeper level. Following discussion in supervision, I felt increased confidence to balance 'not jumping in too quickly', with a need to move conversation on from less relevant topics to achieve the best out of the participant within the time frame. This caused me to reflect upon the amount of power held by researchers during interviews (e.g. deciding what to ask, what to follow up and when to finish the interview) (Kvale, 2006), which I found ironic considering the aim of the research to empower participants. Whilst impossible to entirely remove the inherent power imbalance (Yardley, 2000), I made considerable efforts to reduce its influence, such as constantly 'checking in' with

participants and reassuring them I was interested to hear their views as experts by experience.

As some degree of self-disclosure is unavoidable conducting interviews, I wondered how my age, sex, ethnicity, appearance and status as a clinical psychology doctoral student influenced participant's responses, and whether this encouraged or inhibited participants from sharing certain elements of their experience. Furthermore, as someone who had neither experienced a neurodegenerative condition or neuropsychological assessment (from a patient's perspective), I speculated whether participants may assume my view would be in line with the dominant socio-cultural narratives of illness, including ideas of stigma around cognitive decline (Krendl & Wolford, 2013), burden (Johnson, Sulmasy & Nolan, 2007) and metaphors of being a 'fighter' (Coulehan, 2009) and how this might have played out in their accounts (e.g. was neuropsychological assessment or taking part in the research a way to 'give back' and show they were fighting?). In considering my own epistemological stance, I noticed at times I became influenced by realist ideas about representing 'true' experience, although undoubtedly it was the 'critical' aspect of critical realism that largely influenced the research process, including my interpretations.

#### **4.8. Future Research**

Given that studies focused on a neglected area, there are myriad opportunities for future research. This study has highlighted the value of qualitative approaches, hopefully illustrating and encouraging further qualitative research to enhance the understanding of people's lived experience. To gradually build a picture of larger populations (Smith et al., 2009), this study could be extended to diverse groups that undergo neuropsychological assessment, for instance including people from various cultures and services, and people suffering with various conditions (e.g. stroke, epilepsy, hydrocephalus and encephalitis). It would also be worthwhile conducting further studies focusing specifically on separate neurodegenerative conditions, to achieve greater sample homogeneity and to explore in detail the experience of people with distinct conditions. As each condition is associated with unique patterns of cognitive change and variable

trajectories, it follows that each group, indeed each person, will have unique elements to their experience worthy of consideration, to inform improvements in clinical practice.

Furthermore, considering the multitude of factors that can influence an individual's experience, it would be interesting to conduct comparative studies looking at whether the experience of neuropsychological assessment differs depending on the outcome, the client's pre-morbid ability and the stage of disease progression. This would build on or disprove the hypothesis that people are more likely to report negative experiences of assessment as their disease progresses and performance deteriorates, compared to those in the early stages, and would raise ethical dilemmas as to who should be offered neuropsychological assessment.

In terms of the study's design, IPA provided a preliminary exploration into people's experience without attempting to explain the experience. I reflected that grounded theory, with its focus on generating theoretical explanations (Starks & Brown Trinidad, 2007), could go on to explain 'what factors influence how people manage neuropsychological assessment?'. Alternatively, I wondered whether discourse analysis, with its emphasis on understanding *how* people use language, would have allowed a closer inspection and understanding as to the psychological, medical, social and cultural discourses participants used to describe their experiences and how this impacted on the meaning they attributed to being assessed (Starks & Brown Trinidad, 2007). Alternatively, in a bid to achieve a multi-layered or well-rounded understanding and avoid limitations of any single method, it may be desirable to employ triangulation of the data, using numerous methods (e.g. interviews, observations) from various sources (e.g. patient, clinician, relative) (Yardley, 2000).

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## Appendix A: Information Sheet for Staff

<b>The experience of neuropsychological assessment: views of clients with neurodegenerative conditions</b>
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**Information Sheet for Staff**

There has been little research into experiences of having a neuropsychological assessment, from the viewpoint of a person who has a neurodegenerative condition. The aim of this study is to examine people with neurodegenerative condition's accounts of neuropsychological assessment and how they describe these experiences, in order to improve clinical practice and experiences for other people in the future.

**What is involved?**

- Service users will be invited to attend an interview with the researcher
- The interview will last 40-60 minutes (the researcher can be flexible about time of day of the interview or interview over multiple sessions if necessary)
- The interview will take place in a private room either at the [REDACTED] Hospital, the University of East London or the person's home
- Participants will receive a £10 Love2Shop voucher, plus travel costs of up to £5 will be reimbursed

**Inclusion criteria**

- Age 18+
- Have a neurodegenerative condition (i.e. Parkinson's, multiple sclerosis, motor neurone disease)
- Have undergone a neuropsychological assessment within the past 2 years (and can remember it)!
- Able to speak and understand English
- Able to verbally express themselves sufficiently to answer interview questions
- Have capacity to consent to participating in this research
- Have no other pre-existing cognitive deficit that is unrelated to the potential deficit that was assessed

**Recruitment**

I would be extremely grateful if members of the clinical team can identify eligible service users who might be willing to participate in the study. The initial approach to service users should be made by a member of the clinical team, usually the clinician who knows them best, who can introduce the study and provide potential participants with an information sheet. If they agree to be contacted about the study, the researcher will contact them to discuss the study, answer any questions and arrange to meet with them for the interview if they wish to participate.

If you have an eligible service user who has agreed to be contacted or would like more information, please let me (Hollie Sweetman) know on [REDACTED] or by emailing [u1525563@uel.ac.uk](mailto:u1525563@uel.ac.uk).

Thank you very much for your help!



**Appendix B: Cover Letter**



[DATE]

PRIVATE AND CONFIDENTIAL  
[ADDRESS]

Dear

I am writing to you as I am conducting research with people with neurodegenerative conditions about their experience of having a neuropsychological assessment as part of my doctoral thesis.

I understand that you have undergone a neuropsychological assessment at [REDACTED] Hospital and I would therefore like to invite you to participate in this research study.

I am including a participant information sheet with further details of the research study which may help you think about whether you would like to participate.

Please note, taking part in the research is completely separate to and will not impact on any treatment you are receiving at [REDACTED] Hospital.

As you have agreed to be contacted regarding this study, I will shortly be in touch to answer any questions you may have, and to arrange an appointment if you would like to take part.

Alternatively, if you would like any further information or would like to arrange to take part in this study, please do not hesitate to contact me on [REDACTED] or [u1525563@uel.ac.uk](mailto:u1525563@uel.ac.uk).

I look forward to contacting you shortly.

Yours sincerely

[REDACTED]

**Miss Hollie Sweetman**  
**Trainee Clinical Psychologist**  
University of East London, Water Lane, London E15 4LZ  
Tel: [REDACTED], Email: [u1525563@uel.ac.uk](mailto:u1525563@uel.ac.uk)

Enclosed: Participant Information Sheet

## Appendix C: Participant Information Sheet

### The experience of neuropsychological assessment: views of clients with neurodegenerative conditions



#### Participant Information Sheet

My name is Hollie Sweetman and as part of my clinical psychology training I am researching the experience of having a neuropsychological assessment, from the viewpoint of someone who has a neurodegenerative condition.

I am asking for your help with my research. Below I have answered some questions to help you think about whether you would like to participate in this research study.

#### Why is this study being done?

There has been little research into experiences of having an assessment from the viewpoint of a person who has a neurodegenerative condition. The aim of this research study is to learn about the experience of having a neuropsychological assessment, in order to improve clinical practice and experiences for other people in the future.

#### What is a neuropsychological assessment?

Also known as a cognitive assessment, this was an assessment you underwent which involved a series of pen and paper tests to look at different thinking abilities, such as memory and concentration. On completion of your assessment, you will have received a report detailing your strengths and weaknesses on the tests and whether there have been any changes in your thinking skills.

#### What will I have to do if I decide to take part?

If you take part in the study, I will meet with you and have a conversation about your experience of neuropsychological assessment. I will not be asking about your specific experience with the service at [REDACTED] Hospital, but rather I am interested in your experience of the neuropsychological assessment itself. I will record our conversation (if you agree) to remember what has been said in order to write this up as an anonymous report. The conversation will last approximately 40-60 minutes. The conversation will take place in a private and quiet room, either at your home, at the [REDACTED] Hospital, or at the University of East London.

#### Are there any risks involved?

There are no hazards involved in taking part in this research, although it is possible that you could get upset if you were talking about part of your experience which you found difficult or emotional. If you were to get upset, I would be happy to contact someone at the neuropsychology service for you to talk to. Alternatively, prior to starting the interview I will provide contact details for local

## APPENDIX

support services which you can contact for further support should you wish. You do not have to answer any questions you are not comfortable with and can take a break from the interview at any time and only carry on if you wish to continue.

### **What happens with the things I say? Will they be kept private?**

All the information you provide for the purposes of the study will be anonymised, kept strictly confidential and kept separately from identifying information such as your name. Anonymised data will be kept on a password protected computer, in accordance with the Data Protection Act. Only I will listen to the audio recordings and they will then be typed up. Any names that are mentioned, including yours, and anything you say that would mean someone could identify you will be changed in the typed version.

I have a supervisor from the University who will be supporting me with the study. I will be discussing information from the interviews with them and they may read parts of the transcripts. No one else will be able to read the transcripts. I may talk about more general things relating to the study with a local psychologist who supports the study. The information you provide will not be shared with your care team or GP. After the examination, I will delete the audio recordings. The written transcripts will be kept as a computer file for five years after the study completion, after which time they will be destroyed.

Confidentiality will only be broken if I have serious concerns about your safety or the safety of someone else. In this event, I would have a duty of care to inform someone who may be able to help or may need to know. This may involve consulting with my supervisor so they can advise me. Where possible I would discuss with you first if I was going to break confidentiality.

A small number of quotes from the interviews will be included in the final report. Any identifiable data about you will not be included in any report or publication. This report will be shared with staff at the neuropsychology service, so there could be a chance that someone who knows you might recognise something you said as sounding like you. In order to avoid this happening I will make sure any quotes are carefully selected and not identifiable. The results may later be written up into an article and published in an academic journal.

### **Will I benefit from taking part?**

Taking part is an opportunity to talk about your experience of neuropsychological testing. Your contribution is extremely valuable and has the potential to improve future services for other people. I would be happy to send you a summary of the results once the research is complete – if you would like us to do so please sign the appropriate box on the consent form. As a thank you for your input in the study, each participant who attends an interview will be given a £10 Love2Shop voucher for their time, plus travel costs of up to £5 will be reimbursed.

**Do I have to take part?**

No. It's up to you to decide whether or not to participate in the research. Your usual health care will not be affected by whether you choose to take part or not. Take as long as you need to reach a decision, and please do talk to others about the study if you wish. If you do decide to take part, you will be asked to sign a consent form.

**Can I withdraw from the study once I'm in it?**

If you agree to take part, but later change your mind, you are free to withdraw from the study at any point without having to give a reason. If you withdraw up to 1 week after the interview all of your data will be removed from the study and destroyed. If you withdraw more than 1 week after the interview, then things that you have already shared may be used anonymously in the write-up of the study and any further analysis that may take place. This is because some discussions that I have had with other participants subsequently may only make sense when what you have contributed is included. However, where possible this will be avoided and any information that is used will be summarised and will not use your exact words.

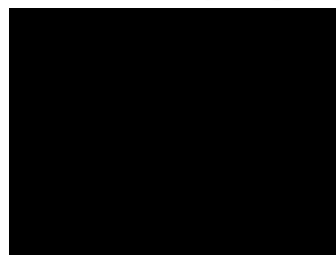
**Who can I contact if I have any questions or would like to take part?**

Should you wish to take part or require further information please do not hesitate to contact me (the researcher) on the details below. Alternatively, you can ask a member of staff at the neuropsychology service to pass on your details to me and I will contact you to arrange an appointment to discuss the study further.

To protect the interests of participants, all research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. This study has been reviewed and given a favourable opinion by Stanmore Research Ethics Committee. If you have any concerns about how the study has been carried out or would like information about complaints procedures, please contact me or the study supervisor below. Alternatively, you can contact the Patient Advice and Liaison Service (PALS) at the Royal London Hospital on 020 3594 2040 or by emailing [pals@bartshealth.nhs.uk](mailto:pals@bartshealth.nhs.uk).

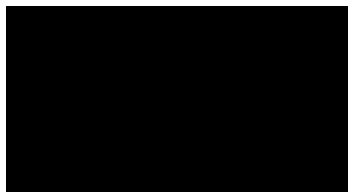
**Researcher**

Hollie Sweetman,  
Trainee Clinical Psychologist,



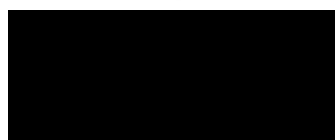
**Study Supervisor**

Dr Matthew Jones Chesters,  
Senior Lecturer,



**Ethics Committee Chair**

Dr Mary Spiller,  
Senior Lecturer,



## Appendix D: Ethics Committee Confirmation Letters



### *Health Research Authority*

London - Stanmore Research Ethics Committee

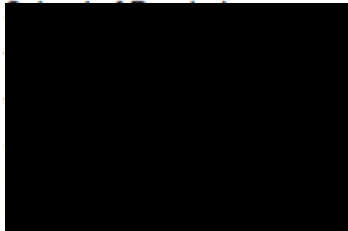
Ground Floor  
NRES/HRA  
80 London Road  
London  
SE1 6LH

Telephone: 020 7972 2561

**Please note:** This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

29 September 2017

Miss Hollie Sweetman  
Trainee Clinical Psychologist



Dear Miss Sweetman

<b>Study title:</b>	<b>The experience of neuropsychological assessment, views of clients with neurodegenerative conditions</b>
<b>REC reference:</b>	<b>17/LO/1474</b>
<b>Protocol number:</b>	<b>n/a</b>
<b>IRAS project ID:</b>	<b>225196</b>

Thank you for your letter of 29 September 2017. I can confirm the REC has received the amended documents requested and that these comply with the approval conditions detailed in our letter dated 21 September 2017.

## APPENDIX

### Approved documents

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEL Indemnity Certificate]	v1	13 July 2017
GP/consultant information sheets or letters [Information Sheet For Staff]	v2	28 September 2017
Interview schedules or topic guides for participants [Interview Schedule]	2	25 May 2017
IRAS Application Form [IRAS_Form_10082017]		10 August 2017
Letters of invitation to participant [Cover Invite Letter]	v2	28 September 2017
Other [Participant Record Form]	1	25 May 2017
Other [List of Support Contact]	1	25 May 2017
Participant consent form [Consent Form]	v3	28 September 2017
Participant information sheet (PIS) [Participant Information Sheet]	v3	28 September 2017
Referee's report or other scientific critique report [Peer Review Feedback]	1	11 January 2017
Referee's report or other scientific critique report [Proceed Letter]	1	11 January 2017
Research protocol or project proposal [Research Proposal]	2	25 May 2017
Summary CV for Chief Investigator (CI) [CV - Hollie Sweetman]	1	25 May 2017
Summary CV for student [CV - Hollie Sweetman]	1	25 May 2017
Summary CV for supervisor (student research) [CV - Matthew Jones Chester]	1	25 May 2017
Summary CV for supervisor (student research) [CV - Ken Gannon]	1	25 May 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>17/LO/1474</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



**Patrick Walsh**  
REC Manager

Copy to:

*Dr Mark Finn*  
*Ms Elizabeth Clough, [Redacted] NHS Trust*



## Health Research Authority

Miss Hollie Sweetman  
Trainee Clinical Psychologist  
University of East London

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

02 October 2017

Dear Miss Sweetman

### Letter of HRA Approval

<b>Study title:</b>	The experience of neuropsychological assessment, views of clients with neurodegenerative conditions
<b>IRAS project ID:</b>	225196
<b>REC reference:</b>	17/LO/1474
<b>Sponsor</b>	University of East London

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.



It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

### Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

### After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### User Feedback



## APPENDIX

IRAS project ID	225196
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The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 225196. Please quote this on all correspondence.

Yours sincerely

Kevin Ahmed (On behalf of Isobel Lyle)

Assessor

Telephone: 0207 104 8171

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Dr Mark Finn, Sponsor contact, University of East London*  
*Ms Elizabeth Clough, R&D contact, [REDACTED] NHS Trust*



4<sup>th</sup> October 2017

Dear Hollie,

<b>Project Title:</b>	<b>The experience of neuropsychological assessment, views of clients with neurodegenerative conditions</b>
<b>Researcher(s):</b>	<b>Hollie Sweetman</b>
<b>Principal Investigator:</b>	<b>Hollie Sweetman</b>

I am writing to confirm that the application for the aforementioned NHS research study reference **17/LO/1474** has received UREC ethical approval and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **4<sup>th</sup> October 2021**. If you require UREC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why UREC approval should be extended.

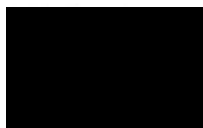
Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please confirm that you will conduct your study in accordance with the consent given by the Trust Research Ethics Committee by emailing [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk).

**Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.**

With the Committee's best wishes for the success of this project.

Yours sincerely,



Catherine Fieulleateau  
Research Integrity and Ethics Manager  
For and on behalf of  
Dr Lisa Mooney  
University Research Ethics Committee (UREC)  
Research Ethics  
Email: [researchethics@uel.ac.uk](mailto:researchethics@uel.ac.uk)

## APPENDIX

From: [REDACTED]  
Sent: [REDACTED]  
To: [u1](#)  
Cc: M  
Subject: [REDACTED]

Dear Ms Sweetman,

Further to the below, I am pleased to confirm **HRA Approval** for the referenced amendment.

You should implement this amendment at NHS organisations in England, in line with the conditions outlined in your categorisation email.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

Please contact [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net) for any queries relating to the assessment of this amendment.

Best Wishes  
Helen

**Helen Penistone**  
**Assessor**  
**Health Research Authority**

[REDACTED]  
T. [REDACTED]  
E. [REDACTED]  
W. [REDACTED]

From: [REDACTED]  
Sent: [REDACTED]  
To: [REDACTED]  
Cc: [REDACTED]  
Subject: IRAS 225196. Amendment categorisation and implementation information|

## Amendment Categorisation and Implementation Information

Dear Miss Sweetman

Thank you for submitting an amendment to your project.

If you have participating NHS/HSC organisations in any other UK nations we will forward the information to the relevant national coordinating function(s).

Please note that you may only implement changes described in the amendment notice.

### What Happens Next?

When available, please forward any other regulatory approvals that are expected for this amendment to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).

### Information Specific to Participating NHS Organisations in England

1. You should now share details of the amendment and, if applicable, amended documents, together with this email, with all participating NHS organisations in England. In doing so, you should include the [NHS R&D Office, LCRN](#) (where applicable) as well as the local research team. A template email to notify participating NHS organisations in England is provided on the [HRA website](#).
2. The participating NHS organisations in England should prepare to implement this amendment.
3. Your amendment will be assessed against [HRA standards](#).
4. Once the HRA assessment has been successfully completed, you will receive an email confirming that your amendment has HRA Approval.
5. You may implement your amendment at all participating NHS organisations in England 35 calendar days from the day on which you provide the organisations with this email and your amended documents (or as soon as the participating NHS organisation confirm that you may implement, if sooner), so long as you have HRA Approval for your amendment by this date. **NHS organisations do not have to confirm they are happy with the amendment.** If HRA Approval is issued subsequent to this date, you may implement following HRA Approval.
6. You may not implement the amendment at any participating NHS organisations in England that requests additional time to assess, until it confirms that it has concluded its assessment.
7. You may not implement at any participating NHS organisation in England that declines to implement the amendment.

## APPENDIX

IRAS Project ID:	225196
REC Reference:	17/LO/1474
Short Study Title:	Experience of Neuropsychological Ax in Neurodegenerative Conditions v1
Date complete amendment submission received:	12/02/2018
Sponsor Amendment Reference Number:	NSA #1 - Removing upper age limit of participants
Sponsor Amendment Date:	12 February 2018
Amendment Type:	Non-Substantial
Outcome of HRA Assessment:	HRA Approval for the amendment is pending. The HRA will separately confirm HRA Approval for the amendment by email.
Implementation date in NHS organisations in England:	35 days from date amendment information together with this email, is supplied to participating organisations (provided HRA Approval is in place and conditions above are met)
For NHS/HSC R&D Office information	
Amendment Category	A

If you have any questions relating to the wider HRA approval process, please direct these to [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

If you have any questions relating to this amendment in one of the devolved administrations, please direct these to the relevant [national coordinating function](#).

Additional information on the management of amendments can be found in the [IRAS guidance](#).

Please do not hesitate to contact me if you require further information.

Kind regards

**Mrs Alka Bhayani**  
**Amendments Coordinator**  
**Health Research Authority**

**E. [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net)**  
**W. [www.hra.nhs.uk](http://www.hra.nhs.uk)**

## Appendix E: Consent Form

**The experience of neuropsychological assessment:  
views of clients with neurodegenerative conditions**



## Consent Form

This form is for you to fill in to show that you have agreed to take part in this study. Please read each section and circle either yes or no to say whether you agree.

▪ Hollie Sweetman has explained this study to me and I understand what she is asking me to do. I have had the chance to read the information sheet and have been given a copy to keep. I have had the opportunity to ask any questions about the study and I have had these answered satisfactorily.	YES / NO
▪ I understand that I do not have to take part and that I can choose to stop whenever I like during the interview and that I may withdraw all my data up to one week after the interview.	YES / NO
▪ I understand that the things I say may be written down and directly quoted in the final report. I also understand that this may later be published but my real name and any other details that may identify me will not be used.	YES / NO
▪ I agree to take part in this study by Hollie Sweetman	YES / NO
▪ I agree to the discussion being audio recorded	YES / NO

Please tick this box if you would like a summary of the findings sent to you following the completion of this study.

☐

\_\_\_\_\_  
Name of Participant  
(BLOCK CAPITALS)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher  
(BLOCK CAPITALS)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Office Use Only  
Participant Identification Number:  
Once completed 1 for participant; 1 for researcher.

Version 3.0 dated 28<sup>th</sup> September 2017



## Appendix F: List of Support Organisations

**The experience of neuropsychological assessment:  
views of clients with neurodegenerative conditions**



### List of Support Organisations

Please find below a list of local support services should you wish to seek further support following our interview.

#### **[REDACTED] Community Neuro Team [REDACTED]**

Address: [REDACTED]  
Tel: [REDACTED]

#### **Compass Wellbeing – Primary Care Psychology Services**

Address: Steels Lane Health Centre, 384-398 Commercial Road, London, E1 0LR  
Tel: 020 7791 3661  
Email: [info@compasswellbeing.co.uk](mailto:info@compasswellbeing.co.uk)  
Website: <http://www.compasswellbeing.co.uk/>

#### **Inspire Mental Health Consortium**

Address: Open House, 13 Whitethorn Street, London, E3 4DA  
Tel: 033 0053 8122  
Email: [enquiry@inspire-wellbeing.org.uk](mailto:enquiry@inspire-wellbeing.org.uk)  
Website: <https://www.inspire-wellbeing.org.uk/>

#### **Mind in [REDACTED] – Advocacy Service**

Address: [REDACTED]  
Tel: [REDACTED]  
Email: [REDACTED]  
Website: [REDACTED]

#### **SANE/Saneline**

Address: St Mark's Studios, 14 Chillingworth Road Islington, London, N7 8QJ  
Tel: 0300 304 7000 (SANEline)  
Email: [info@sane.org.uk](mailto:info@sane.org.uk)  
Website: [www.sane.org.uk](http://www.sane.org.uk)

#### **Samaritans**

Postal Address: Freeport RSRB-KKBY-CYJK, PO Box 9090, Stirling, FK8 2SA  
Tel: 116 123 (FREE to call – you don't have to be suicidal to call)  
Email: [jo@samaritans.org](mailto:jo@samaritans.org)  
Website: <http://www.samaritans.org/>

#### **Rethink**

Postal Address: FREEPOST Rethink Mental Illness  
Tel: 0300 5000 927  
Email: [info@rethink.org](mailto:info@rethink.org)  
Website: <https://www.rethink.org/>

**Huntingdon's Disease Association**

Address: Suite 24, Science Park IC1, 131 Mount Pleasant, Liverpool, L3 5TF

Tel: 0151 331 5444

Email: [info@hda.org.uk](mailto:info@hda.org.uk)

Website: <https://hda.org.uk/>

**Motor Neurone Disease Association**

Address: David Niven House, 10-15 Notre Dame Mews, Northampton, NN1 2BG

Tel: 01604 250505

Email: [enquiries@mndassociation.org](mailto:enquiries@mndassociation.org)

Website: [www.mndassociation.org](http://www.mndassociation.org)

**Multiple Sclerosis Trust**

Address: Spirella Building, Bridge Rod, Letchworth Garden City, Herts, SG6 4ET

Tel: 01462 476700

Email: [info@mstrust.org.uk](mailto:info@mstrust.org.uk)

Website: <https://www.mstrust.org.uk/>

**Parkinson's UK**

Address: 215 Vauxhall Bridge Road, London, SW1V 1EJ

Tel: 0808 800 0303

Email: [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)

Website: <https://www.parkinsons.org.uk/>

You can also contact your GP, who may be able to refer you to other services.



## Appendix G: Interview Schedule

### Interview Schedule

#### Introduction [Before turning on recorder]

- Introduce myself
- Icebreaker questions: "How was your journey here?"
- Summarise the participant information sheet verbally (in particular anonymity, confidentiality and its limits).
- "Do you have any questions?"
- Go through consent form and sign if participant happy to proceed
- "Would you like a summary of the findings?" If so ensure they have ticked box on consent form
- Ask for demographic information
- Agree an approximate length of interview. Reminder that you can have a break, reschedule or withdraw at any time during the interview and up to one week afterwards. "How would you let me know if you did not wish to answer a question or continue with the interview?"
- Provide contact details for further support
- Reiterate there is no right or wrong – more interested in hearing about your experience
- "I may make some notes of things I want to come back to"

#### Interview Questions [Turn on recorder]

##### **1. Tell me about the neuropsychological assessment you underwent?**

- Prompts:
- When was the assessment?
  - What was the purpose of the assessment?
  - Why was it arranged? What were the aims?
  - What had you been told as to why you were being assessed?
  - Who booked/arranged it for you?

##### **2. Tell me, what was your experience of being assessed?**

- Prompts:
- What do you remember of the assessment?
  - How did it feel?
  - What was it like for you?
  - What was it like being in the room?
  - Are there parts that you particularly remember?
  - Were there any qualities of the examiner that were helpful/unhelpful?

##### **3. Tell me, what were the main results of the assessment?**

- Prompts:
- Were you told the results?
  - What were the main findings?
  - What did the examiner tell you about the results of the assessment?
  - Were they explained to you?

##### **4. What were the outcomes of the assessment?**

- Prompts:
- Was it a helpful/unhelpful process?
  - Has it changed how you view yourself or actions?
  - What happened as a result?
  - What was the most/least helpful thing about the assessment?
  - Were the results meaningful for you/family/carers?
  - Did you learn anything? Did anything change?
  - Did any of the assessment make you feel better/worse?

**5. Is there anything else you would like to share with me about your experience of the neuropsychological assessment?**

Prompts

- Please, tell me more.
- What do you mean?
- What was that like for you?
- How does that make you feel?
- How do you feel about that?
- Can you give me an example?

Debriefing [Turn recorder off]

- "How do you feel about the conversation we have just had?"
- "Do you have any questions? You can email me if you think of any questions after you leave."
- "Is there anything that concerned you about the conversation?"
- "Is there anything that you would like me to leave out of my final report?"
- "Do you have any suggestions about how I could improve the interview?"
- Reminder to use contact details for support organisations if they would like to talk to someone later on.

Field Notes

- Any notable themes?
- Setting characteristics?
- Participant characteristics? (physical appearance, fatigue, shy, talkative, embarrassed)
- Researcher characteristics? (my perceptions of person, my thoughts, feelings)
- Any notable events?
- Context? (social, historical, political, policy)
- Any changes to interview schedule?

## Appendix H: Participant Record Form

<b>The experience of neuropsychological assessment: views of clients with neurodegenerative conditions</b>
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## Participant Record Form

Date:

Time:

*Answers to these questions will help us to know more about the people we have interviewed and make sure that we have talked to people from different backgrounds and with different experiences. This information will be kept anonymous and not be linked to your name.*

1. What is your age? \_\_\_\_\_
2. What gender do you identify with?  
☐ Male    ☐ Female    ☐ Other (please describe) \_\_\_\_\_
3. What is your ethnicity? \_\_\_\_\_
4. What neurodegenerative condition have you been diagnosed with?  
 \_\_\_\_\_
5. How long ago were you diagnosed? \_\_\_\_\_
6. When was your neuropsychology assessment (approx.)? \_\_\_\_\_  
 \_\_\_\_\_

PLEASE NOTE: This will not be stored with the interview transcripts and all names, and other identifying information will be destroyed following examination of the research.

Office Use Only

Participant Identification Number:

Version 1.0 dated 25<sup>th</sup> May 2017

**Appendix I: Simple Transcription Scheme (Adapted from Bannister et al., 2011)**

(.)	One second pause
(..)	Two second pause
(...)	Three second pause
(4)	For pauses longer than four seconds
=	No gap between speakers
/	Denotes people speaking at the same time
....	Lengthening of a sound
tr-trail off	Person trails off or doesn't finish a word
<u>emphasis</u>	Words spoken with more emphasis than others
LOUD	Loud sounds
(.hhh)	Audible in-breath
(Hhhhh)	Audible out-breath
[sounds/action]	Sounds of actions during interview e.g. [both laugh]
[inaudible]	Inaudible section of transcript
[identifiable information]	Any information that may identify a participant e.g. a person's name, a location
I:	Denotes the interviewer

To protect participant's confidentiality, pseudonyms were assigned and used in the transcripts and quoted in the thesis alongside line numbers e.g. (John, 124) (pseudonym, line number).

134	- A/an <u>anxiety</u> <u>implying</u> <u>to</u> <u>process</u> .	fun, it was fun, even when it was impossible it was fun. I'm quite competitive, so er, I would you know (.)	It was fun, despite challenge. Emphasis on 'was' - having to be is competitive. Tally off. persuade that it 'was' fun.
135	- A <u>playful</u> <u>competition</u> <u>against</u> <u>himself</u> <u>or</u> <u>others</u> .	I: You said earlier, so I might come back to a few things that you've said. You said "it was intense", and I just wonder if you can tell me more about...	Competitive against who? So perhaps I wasn't. Or there was a 'but'.
136		P2: A lot of people come round here to see me, um from [the community neuropsychology service] so, speech therapist, occupational health, people like yourself, and so they come round and it's always pleasurable, so it's, everyone's very nice, good at their jobs and hopefully I'm giving people a warm welcome and we get to whatever we need to do. This was different, this was, you know, (.) a chan-, a real change in, we've got the, we've got the clock on, we've got a, you can look at these for a minute and then I'll take them away, so it's it's quite comp-, you know the-the intense, so that the intensity of a series, an exam setting is obviously an intense thing isn't it, so, and then actually when you get into it, there was some really difficult stuff in there, so yea you know, I said to you I'll do these things and I'll do them properly so, I was quite up for it and [inaudible-20:19:20]	Metaphor of competition - like a game, a sports event. A fun event in which to compete against others. If you gain trophy, recognition from others. If lose, try harder next time. Is neuropsych like a game?
137		I: Up for the challenge!	Is neuropsych like a game?
138		P2: Well also I'm in familiar surroundings and I've got distractions going on and that monologue, [laughter] that sort of conversation, so it's quite intense. So, when I can't do something I'm I'm thinking 'why couldn't I've done that, what what does that...', I'm trying to find, and um through a lot of the session it's trying to find the pattern, or the key to unlock it, so you know it's, the tests need some intense thinking in order to crack, to	Metaphor of competition - like a game, a sports event. A fun event in which to compete against others. If you gain trophy, recognition from others. If lose, try harder next time. Is neuropsych like a game?
139			Metaphor of competition - like a game, a sports event. A fun event in which to compete against others. If you gain trophy, recognition from others. If lose, try harder next time. Is neuropsych like a game?
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166			Metaphor of competition - like a game, a sports event. A fun event in which to compete against others. If you gain trophy, recognition from others. If lose, try harder next time. Is neuropsych like a game?
167			Metaphor of competition - like a game, a sports event. A fun event in which to compete against others. If you gain trophy, recognition from others. If lose, try harder next time. Is neuropsych like a game?
168			Metaphor of competition - like a game, a sports event. A fun event in which to compete against others. If you gain trophy, recognition from others. If lose, try harder next time. Is neuropsych like a game?

<p>169 - Intersectronality of intensity</p> <p>170 - Feeling exposed</p> <p>171</p> <p>172</p> <p>173</p> <p>174</p> <p>175</p> <p>176</p> <p>177</p> <p>178 - Change in perception following diagnosis</p> <p>179</p> <p>180</p> <p>181</p> <p>182</p> <p>183</p> <p>184</p> <p>185</p> <p>186</p> <p>187</p> <p>188</p> <p>189</p> <p>190</p> <p>191</p> <p>192</p> <p>193</p> <p>194</p> <p>195</p> <p>196</p> <p>197</p> <p>198</p> <p>199</p> <p>200</p> <p>201</p> <p>202</p> <p>203</p> <p>- Lowered tolerance</p> <p>- Reminiscence re. past challenges</p> <p>- Awareness of cognitive difficulties</p> <p>- Contradictory desires</p> <p>- accuracy vs. good score</p>	<p>solve them (...) so there's all sorts of intensity at all levels going on. Well this is a really weird look into my head isn't it [laughter].</p> <p>I: No, that's exactly what were what we're wanting. There's noth-, like I said, there's kind of no, there's no right or wrong way to be, so whatever was your experience is, is um yeah what we're looking for really.</p> <p>P2: Yea. But th-th-th-there's a definite exper-, there's a definite how the world sounds and looks differently to before I had [a neurodegenerative condition]. It, I don't know what it is, it's like someone just flipped a switch ever so slightly and the world looks and sounds different to me (...)</p> <p>and everything I do is compl-, I do it in a different way and it looks and feels, it's quite, it's it's really difficult to describe. I've tried to do it before and I can't, but there's definitely like some-somebody just flipped a switch and it's-</p> <p>I: You just know you're seeing things slightly differently.</p> <p>P2: Yea/ now there's a hum, a permanent hum in my ears and there isn't, but that's what it feels like, like I've sand in my socks or something.</p> <p>Everything's slightly more uncomfortable, slightly harder to grab (...), everything's slightly more annoying (...), so with that in mind the tests I knew were quite a challenge. They would have been to a normal [redacted] year-old man I think, but to me with you know, sort of feeling sort of handicapped in in a cognitive way, I wanted to do well, or certainly wanted to be an accurate score (...) it's important, so the tha-that that too-, all that generated the intensity.</p> <p>I: That, what did you say?</p>	<p>Intensity. Intersectronality - multiple things cross-feeding. Awareness of potential judgement. Laughter - feels uncomfortable. Feels exposed, that I will judge, that his experience is inward. Don't often share + this making into can head - need experience to share.</p> <p>Repetition (chwh) - trying to get words out with conviction. Perception different following diagnosis. Now that deterioration + death have been introduced.</p> <p>→ Should be?</p> <p>Use of flipped a switch: Electrical - suddenly turned on.</p> <p>Emphasising how 'different' it is.</p> <p>Difficulty describing.</p> <p>Awareness his descriptions aren't reality. 'Isn't doesn't want me to think he's going mad. A constant weight on his shoulder. Never feeling fully at peace.</p> <p>Less tolerance. Repetition x 3 - emphasising. Less tolerance for tests, hence frustration. A neurodegenerative condition means you have less tolerance of test - at this time the tests were challenging. Partly due to age, partly condition describing extra, layers of impairment. I knew beforehand difficult anyway, but now even more. So easier in life - he's used to prove can still do well. He felt cognitively handicapped, priced up cognitive challenge would be what made him feel this - being told that made him feel that.</p> <p>Contradiction - accuracy vs. good score. Well which does he want - ideally both, but reality that it may not be possible. It's important - but not necessarily what you want to hear. Use of words generated. Electricity references a pain.</p> <p>Danger. A circuit that should work - no longer does. Or common cultural use of these metaphors.</p>
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## Appendix K: Audit Trail of Themes

Initial Phase

Super/subordinate Themes	Elements of Themes
<b>Hopes / expectations of the process</b>  <b>Anticipating possible outcomes</b>	<b>Hopes / expectations of the process</b> Seeking knowledge and empowerment To measure progression Objectivity of assessment Uncertainty Expectation 'should' do assessment <b>Anticipating possible outcomes</b> Confirmation of cognitive decline
<b>Communication style</b>     <b>Familiarity</b> <b>Expertise</b>	<b>Communication style</b> Conscientious Collaborative Respectful Put people at ease Good communication Empathy allows vulnerability Openness Unheard, misunderstood Hesitancy to break bad news <b>Familiarity</b> Familiarity builds trust <b>Expertise</b> Expertise Opinion held weight
<b>Positive aspects</b> <b>Mixed aspects</b> <b>Negative aspects</b>    <b>Environment</b>  <b>Awareness of performance</b>	<b>Positive aspects</b> Pleasant <b>Mixed aspects</b> Unusual <b>Negative aspects</b> Time pressure Intensity Requires concentration Lengthy, repetitive Interrogated re education <b>Environment</b> Comfortable Distractors problematic <b>Awareness of performance</b> Retained ability Exposing lost ability Failures salient as confirming problem Performance relative (to self and others)

## APPENDIX

<p><b>Response to testing</b></p>	<p><b>Response to testing</b></p> <p><b>- Emotional</b></p> <p>Curiosity</p> <p>Confident, resilient</p> <p>Stressful, frustrated</p> <p>Self doubt</p> <p>Self punishing</p> <p><b>- Thought Process</b></p> <p>Meta thinking process simultaneously occurring</p> <p>Questioning reason for perceived poor performance</p> <p><b>- Coping</b></p> <p>Attempt to identify strategies</p> <p>Protect self from failure</p> <p>Defence mechanisms</p>
<p><b>Power and control</b></p>	<p><b>Power and control</b></p> <p>Empowered if fully briefed</p> <p>Passive recipient</p>
<p><b>Positive outcomes</b></p>	<p><b>Positive outcomes</b></p> <p>Understandable</p> <p>Reconfirmation of retained self identity</p> <p>Reassurance no fundamental problems</p> <p>Proof of own sanity</p> <p>Proof not lazy</p> <p>Externalised burden</p>
<p><b>Negative outcomes</b></p>	<p><b>Negative outcomes</b></p> <p>Report technical</p>
<p><b>Time sensitive</b></p>	<p><b>Time sensitive</b></p> <p>Frustration at unexplained delay exacerbated by limited life expectancy</p>
<p><b>Emotional impact</b></p>	<p><b>Emotional impact</b></p> <p>Therapeutic</p> <p>Reconnection to hope</p> <p>Frustrated / scared re lost ability</p> <p>Low mood / grieving loss</p> <p>Mixed / changeable</p>
<p><b>Coping strategies provide power and control</b></p>	<p><b>Coping strategies provide power and control</b></p> <p>Facilitated coping</p> <p>Gained strategies to compensate</p> <p>Lack of strategies disappointing</p> <p>Ability to understand provided power</p> <p>Knowledge empowering</p> <p>Allowed adjustment and acceptance</p>
<p><b>Family</b></p>	<p><b>Family</b></p> <p>Increasing family's insight</p> <p>Seeking family's care</p>



## APPENDIX

<b>Future</b>	<b>Future</b> Preparation for future Continued uncertainty re future progression
<b>Implications</b>	<b>Implications</b> Increased self-doubt over work performance Loss of roles Permission giving to change role

**Middle Phase**

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>	<b>Elements of Themes</b>
<b>Expectations of assessment</b>	<b>To measure cognitive decline</b>  <b>Anticipating understanding and coping advice</b>  <b>Pressures and fears</b>	To find and confirm 'hidden' cognitive decline To measure progression  <b>Seeking understanding and coping</b> Seeking knowledge / understanding / explanation Advice on coping  Anticipating possible outcomes Expectation 'should' do assessment
<b>Relationship with clinician</b>	<b>Positive clinician qualities</b>  <b>Clinician supported coping</b>  <b>Familiarity and trust</b>  <b>Expertise and power</b>	<b>Communication style</b> Conscientious Collaborative Respectful Good communication Openness Unheard, misunderstood  <b>Helped coping</b> Put people at ease Empathy allows vulnerability Hesitancy to break bad news  Familiarity builds trust  Expertise Opinion held weight
<b>Experience during testing</b>	<b>Awareness of performance</b>	Grateful for retained ability Exposing lost ability Failures salient as confirming problem

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	<b>Psychological response to testing</b>	<b>- Thought Process</b> Meta thinking process simultaneously occurring Questioning reason for perceived poor performance <b>- Emotional</b> Curiosity Confident, resilient Stressful, frustrated Self doubt Self punishing
	<b>Coping with testing</b>	<b>- Coping</b> Resilience (attempt to identify strategies) Denial (protect self from failure / defence mechanisms)
	<b>Intense and prolonged</b>	Time pressure Intensity Requires concentration Lengthy, repetitive Interrogated re education Passive recipient Similarity to school
	<b>Importance of environment</b>	Comfortable Distractors problematic
<b>Outcome of assessment</b>	<b>Communication of results</b>	Empowered if fully briefed <b>Negative outcomes</b> Report technical <b>Time sensitive</b> Frustration at unexplained delay exacerbated by limited life expectancy <b>Family: Involvement</b>
	<b>Understanding of results</b>	<b>Positive outcomes</b> Understandable Reconfirmation of retained self identity Reassurance no fundamental problems Proof of own sanity Proof not lazy Proof not mad Externalised burden

## APPENDIX

		<b>Objectivity of assessment</b> <b>Family:</b> Increasing family's insight Seeking family's care
	<b>Emotional impact</b>	Therapeutic Reconnection to hope Frustrated / scared re lost ability Low mood / grieving loss Mixed / changeable <b>Family:</b> Shared relief <b>Reality breaks defences</b> <b>Feel during, process after</b>
	<b>Coping strategies provided power and control</b>	Facilitated coping Gained strategies to compensate Lack of strategies disappointing Ability to understand provided power Knowledge empowering Allowed adjustment and acceptance
	<b>Future implications</b>	Preparation for future Continued uncertainty re future progression (concern re future madness) Increased self-doubt over work performance Loss of roles Permission giving to change role

**Final Stage**

<b>Superordinate Themes</b>	<b>Subordinate Themes</b>
<b>Expectations of assessment</b>	<b>Deciding to undergo assessment</b> <b>To measure cognitive decline</b> <b>Anticipating understanding and coping advice</b>
<b>Relationship with clinician</b>	<b>Positive clinician qualities supported coping</b> <b>Familiarity and trust</b> <b>Expertise and power</b>
<b>Experience during testing</b>	<b>Subjective awareness of performance</b> <b>Emotional response to testing</b> <b>Coping with testing</b> <b>Intense and prolonged</b> <b>Importance of environment</b>
<b>Outcome of assessment</b>	<b>Communication of results</b> <b>Meaning of results</b> <b>Emotional impact of results</b> <b>Coping strategies provided power and control</b> <b>Future implications</b>

# APPENDIX

## Appendix L: Matrix Identifying Recurrence of Themes Within Participant's Accounts

	Helen	Stephen	Sheila	Jean	Graham	Wendy	Lisa	Arthur	Total
<b>Expectations of assessment</b>									
Deciding to undergo assessment	✓	✓	x	✓	x	✓	✓	✓	6
To measure cognitive decline	✓	✓	✓	✓	x	✓	✓	✓	7
Anticipating understanding and coping advice	✓	✓	✓	✓	x	✓	✓	✓	7
<b>Relationship with clinician</b>									
Positive clinician qualities supported coping	✓	x	✓	✓	✓	✓	✓	✓	7
Familiarity and trust	x	✓	x	✓	✓	x	✓	x	4
Expertise and power	✓	✓	x	x	x	✓	✓	x	4
<b>Experience during testing</b>									
Subjective awareness of performance	✓	✓	✓	✓	✓	✓	✓	✓	8
Emotional response to testing	✓	✓	✓	✓	✓	x	✓	✓	7
Coping with testing	x	✓	✓	x	✓	✓	✓	✓	6
Intense and prolonged	✓	✓	✓	✓	x	✓	✓	x	6
Importance of environment	x	✓	✓	✓	x	x	✓	x	4
<b>Outcome of assessment</b>									
Communication of results	✓	✓	✓	✓	x	✓	✓	✓	7
Meaning of results	✓	✓	✓	x	✓	x	✓	x	5
Emotional impact of results	✓	✓	✓	x	✓	x	✓	x	5
Coping strategies provided power and control	✓	x	✓	✓	✓	✓	✓	✓	7
Future implications	✓	✓	x	x	x	x	✓	x	3